
20TH BIENNIAL CONFERENCE OF THE EUROPEAN SOCIETY FOR HEALTH AND MEDICAL SOCIOLOGY (ESHMS)

Intersectionality and Inclusion in Health

BOOK OF ABSTRACTS

*This conference has been co-financed by the Research Foundation Flanders (FWO), University of Antwerp,
Free University of Brussels and the City of Antwerp*

CONFERENCE SCHEDULE

2 July

	K.001	M.106					
09:00-17:00		Early career workshop (location: Sint-Jacobstraat 2, 2000 Antwerpen)					
16:00-18:00	Participant registration (location: Kleine Kauwenberg 14, 2000 Antwerpen)						
18:00-20:00	Welcome reception @ City Hall Antwerp (location: Grote Markt 1, 2000 Antwerpen)						

3 July

	K.001	K.101	K.102	K.103	K.201	K.202	K.203
08:00-09:00	Welcome coffee and registration (Foyer, K-Building)						
09:00-09:50	Opening Ceremony						
09:50-10:50	Keynote: Stephani Hatch – <i>How Inclusive Practices Can Accelerate the Pace of Change in Tackling Social Inequities & Health</i>						
11:00-12:30		Going Graphic: Understanding the Potential of Comics & Visual Storytelling to Improve Health Narratives	Cultural Sensitive Healthcare Services	Health Behaviors and Lifestyle	Gender and Health	Migration and Ethnicity in Health	Intersectionality and Syndemics: Theoretical and Methodological Challenges
12:30-13:30	Lunch						
13:30-15:00		Global Health	Health Behaviors and Lifestyle	Gender and Health	Migration and Ethnicity in Health	Healthcare Access and Equity	Intersectionality and Syndemics: Theoretical and Methodological Challenges
15:00-15:30	Coffee Break						
15:30-17:00		Healthcare Access and Equity	Cultural Capital & Food-Related Practices	Methodological Challenges in Medical Sociology Research	Migration and Ethnicity in Health	Health Policy and Systems	Medicalization and Demedicalization
17:10-18:10	Meet the Editors Workshop	Creative workshop (until 18:30)			Inequalities in Cognitive Functioning: Intersectional & International Perspectives	Bourdieuian Field of Power and Health	Making Impact through Multistakeholder Collaboration

4 July

	K.001	K.101	K.102	K.103	K.201	K.202	K.203
08:30-10:00		Intersectional Perspectives on Family Health	End of Life	Sexual and Reproductive Health	Social Inequalities in Healthcare Use	Socioeconomic Status and Health	Labor, Work, Health and Inclusion
10:00-10:20	Coffee Break						
10:20-11:20	Keynote: Charles Agyemang - <i>Cardiovascular disease burden in migrant populations in Europe: Lessons from the RODAM study.</i>						
11:30-13:00		Activism Presentations	Ageing and Health	Sexual and Reproductive Health	Social Inequalities in Healthcare Use	Socioeconomic Status and Health	Labor, Work, Health and Inclusion
13:00-14:00	Lunch (poster presentations)						
14:00-15:00	Round table: Discussing the publication landscape						
15:00-15:30	Coffee Break						
15:30-17:00		Public Health and Prevention	Healthcare Workforce	Family Dynamics and Health	Health Disparities: Exploring the Reciprocal Relationship between Health and Social Inequality	Reconsidering Digital Ageing: Boundaries, Transformations and Meanings	Studying (non-) participation in Health Research: Experiences, Research and Theories
19:00-23:00	Social Dinner @ Horta						

5 July

	K.001	K.101	K.102	K.103	K.201	K.202	K.203
08:30-10:00		Mental Health	Technology and Health	Combining Employment and Informal Care for the Aged	Comparative Approaches in Analyzing Social Inequalities in Health – Universal Patterns, Cross-Country Differences and Societal Change	Life Course Perspectives on Health	Studying (non-) Participation in Health Research: Experiences, Research and Theories
10:10-11:10	Keynote: Andrew Bell - <i>The intersectional MAIHDA approach: what does it do, what can it do, and what is it unable to do?</i>						
11:10-11:30	Coffee break						
11:30-13:00		Intersectional Perspectives on Family Health	Ageing and Health	Pandemics and Health	Social Inequalities in Healthcare Use	Preventive Health (Inequalities): Enhancing our Understanding Through Adopting Sociological Theories	Gender and Health Prevention: Questioning, Measuring, Evaluating... Transforming?
13:00-14:00	ESHMS General Assembly (starts at 13:15)	Lunch					
14:00-15:30		Pharmaceuticalization	Mental Health	Technology and Health	Intersectional Disparities in Health and Illness	Life Course Perspectives on Health	Studying (non-) Participation in Health Research: Experiences, Research and Theories
15:40-16:30	Closing Ceremony						

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3 July

3 July: 9:00 – 9:50

Opening Ceremony – *Room K.001*

Welcome by Rector of The University of Antwerp: Herman Van Goethem, by ESHMS President Stéphane Cullati, and the organizing committee: Sarah Van de Velde, Nina Van Eekert & Veerle Buffel

Presentation of the Results of the International Survey of Health and Medical Sociology in Europe: Valeria Quaglia

3 July: 9:50 – 10:50

Keynote: Stephani Hatch – *Room K.001*

How Inclusive Practices Can Accelerate the Pace of Change in Tackling Social Inequities & Health

Professor Stephani Hatch's research focuses on population mental health, inequalities in mental health and health services, discrimination and other sources of social adversity. Prof. Hatch leads many research projects within these domains, including the Tackling Inequalities and Discrimination Experiences in Health Services (TIDES), and co-leads the Marginalised Communities and Mental Health program within the ESRC Centre for Society and Mental Health, and the Health and Social Equity Collective. She also holds national and international trustee and advisory roles across academic, health and community sectors.

Prof. Hatch is the Vice Dean for Culture, Equality, Diversity & Inclusion and a Professor of Sociology and Epidemiology at the Institute of Psychiatry, Psychology & Neuroscience, King's College London. She leads the Health Inequalities Research Group; an interdisciplinary research program that integrates inclusive and collaborative approaches to knowledge production, training, dissemination, action and outreach. The group is supported by Wellcome, the Economic and Social Research Council, and Impact on Urban Health, part of Guy's and St Thomas' Foundation.

3 July: 11:00 – 12:30

Going graphic: Understanding the Potential of Comics and Visual Storytelling to Improve Health Narrative, Thematic session – Chair: Veronica Moretti – *Room K.101*

In the body, on the body: Understanding body donation through graphic medicine

Annalisa Plava (University of Bologna)

Introduction

Body donation is fundamental in medical research and education. Human anatomy teaching based on cadaver dissection is at the base of medical training worldwide. However, in Italy whole-body donation is still limited and complicated. Some socio-cultural factors (age, education, religion, culture, personality characteristics and personal relation with death) and the unawareness of the potential donors may hinder or limit this possibility.

Therefore, appropriate information and awareness-raising campaigns are needed. With the aim of expanding information and awareness towards the importance of the whole-body donation but also to support medical education and research, an interdisciplinary team (sociologists, physicians, artists) is leading an experimental project at the University of Bologna introducing Graphic Medicine (GM).

Methodology

The immersive fieldwork and key informants' perspectives were the starting point for drawing attention to the importance of comics-based research for the education and continuing training of medical students and medical professionals; for the information and raising awareness among the general population and for understanding how the tool of comics could bring out the different perspectives: educational, formative, values, social. To create the graphic novel - a direct output of the narratives - the empirical social research emerged was analyzed in a constant and iterative dialogue with Medical and Fine Arts interlocutors. The conceptual maps in which the perspectives from which body donation was observed were built by choosing common argumentative labels, themes, phrases, recurring concepts. Then, the narrative storyboard and the synoptic tables - descriptive and visual sections where one anatomical part is examining in depth - in coherence with each storytelling were created.

The storyboard of the graphic novel starts from the stories, points of view, perceptions, value but also from the technical and artistic sensitivity attributions of the various actors involved in the research. Activating, in this regard, a specific understanding, listening and support in the body, on the body, among bodies.

Results

Overall, the results of this ethno-graphic experience illustrate whole body donation - particularly the Italian at the University of Bologna - as an example of training and educational learning process. The technical and socio-cultural complexity brings this topic closer to comics in order to find a more immediate way of knowledge and dissemination. The involvement of social researchers and artists in the dialogue with the medical environment together with the construction of a network of key informants around the topic created a collaborative model based on practices, relationships, inclinations and obstacles that not only have narrated but also visualized the process of body donation. In this way, the construction of an instrument such as the graphic novel has not only created a meeting ground between seemingly distant disciplines such as medicine, art and sociology, but has also stimulated reflections with embodied, communicative, informative and awareness-raising implications. Therefore, graphic novel aims to 1) expand the narratives of students and experts showing the importance of medical research; 2) act as a resource for different scientific communities and other actors supporting and interacting with the issue of body donation 3) be a further strategy to raise awareness of whole-body donation in Italy, trying to reach a wider audience and not only an academic one.

Conclusion

In Italy, knowledge of whole body donation is still very limited and only a few Centers have an active program creating limits to health education and scientific research based on cadaveric dissection. The graphic novel offers real experiences fragments in an active involvement of the reader, which recalls the interaction between observer and observed, between researcher and participants, and makes the expressive medium so effective. Future studies could be oriented towards exploring, the potential of graphic novels and comics as a social science research method to support the investigation of complex phenomena, as a pedagogical tool to collect data on the effectiveness in changing the public's attitude towards body donation and, considering the universal value of body donation, as a communication and awareness-raising strategy.

The use of graphic medicine to empower healthcare professionals to address vaccine hesitancy

Joana Mendonça (Instituto de Ciências Sociais da Universidade de Lisboa), [Ana Patrícia Hilário](#) (Instituto de Ciências Sociais da Universidade de Lisboa)

Introduction

There is evidence that in the vaccination encounter in Portugal healthcare professionals usually employ a paternalistic model of communication, adopting an authoritarian tone and devaluing parents' concerns, namely

regarding vaccines' efficacy and side effects. This model of communication has been proven ineffective to address vaccine hesitancy as it fuels vaccine hesitant parents' distrust in healthcare professionals. Therefore, this model of communication should be replaced by person-centered approach which recognizes the singularity of each child and family and using communication skills such as empathy and active listening. The versatility of graphic medicine makes it suitable to work on challenging predefined models. Therefore, the current study intends to show graphic novels can be useful in the context of vaccine hesitancy.

Methodology

A graphic novel was designed and presented in a workshop with 66 healthcare professionals. In the first part of the graphic novel the findings of the XXX project were presented, stressing the prevailing paternalistic model of communication; in the second part, the motivational interviewing was illustrated as an alternative communication approach. These opposing communication models were depicted in a graphic novel in the format of a pocketbook, illustrating a vaccine encounter between a nurse and a couple of parents of a newborn baby in a nursing practice setting. In the first part, this encounter was depicted through the paternalistic model of communication lens, and, in the second part, the motivational interviewing approach was used instead. The graphic novel was distributed to all participants, allowing them to reflect and comment on the differences between the two communication models portrayed, and, ultimately, on their own practices (Green & Myer, 2010).

Results

The graphic novel appeared to be a useful elicitation tool for knowledge on vaccine hesitancy among healthcare professionals. Indeed, it may encourage healthcare professionals to develop a more empathic approach towards vaccine hesitant parents, as well as contribute to the acquisition of new communication tools such as the motivational interviewing approach. The results are aligned with previous research which have suggested that graphic novels can help healthcare professionals to build empathy with patients. Nevertheless, no studies to date have acknowledge this role regarding vaccine hesitant parents. The use of text and images in the graphic novel facilitated the development of a connection with vaccine hesitant parents by healthcare professionals. Furthermore, the graphic novel presented proved to be a creative way for healthcare professionals to learn about the motivational interviewing technique. Healthcare professionals became more aware of the impact of their communication in the vaccination encounter.

Conclusions

The use of a graphic novel in the context of vaccine hesitancy proved to be an effective and creative tool to improve the communication of healthcare professionals in the vaccination encounter. The graphic novel enabled the learning of a new communication strategy, as well as to increase the empathy of healthcare professionals towards vaccine hesitant parents. This study explored, for the first time, the use of graphic medicine to promote healthcare professionals' communication skills to effectively address vaccine hesitant parents in Portugal.

Compassion comics: Exploring interrelated mechanisms of empathy & compassion in graphic medicine through mindfulness-based compassion.

Octavia Roodt (Catholic University Leuven)

Abstract

I propose to demonstrate the potential of mindfulness-based compassion theories to better understand the role of empathy and compassion within graphic medicine interventions. While the use of comics in health care is purported to promote empathy (Li and Gray, 2023), compassion training transforms empathy into a nuanced, sustainable and proactive stance to vulnerability (Lindow, Gisch and Marchini, 2023). Specifically, comics interventions that actively seek to promote compassion through mindfulness-based techniques may build trust, engage vulnerable groups and support caregiving activities by defining and promoting compassionate frames in care environments.

The necessity of compassion for providing optimal care is increasingly recognized (Trzeciak, Roberts and Mazzarelli, 2017; Sinclair et al., 2022; Jemal et al., 2023). Caregiving is a response to another's need, within a mesh of complex collective needs and responsibilities (van Nistelrooij and Visse, 2019). Responding with compassion involves maintaining equanimity while being open and attentive to another's suffering (Seppälä et al., 2017). Compassion is linked to person-centered care, carer wellness and trust-building (Cox, 2011; Frampton, Guastello and Lepore, 2013; van der Cingel, 2014). Compassion is measurable, trainable and improves outcomes for both caregivers and those receiving care, enhancing care quality and the surrounding financial margins such as patient adherence, safety and satisfaction (Lains, Johnson and Johnson, 2024).

Multidisciplinary compassion theories distinguish empathy as a precursor to compassion and a distinct phenomenon (Halifax, 2012; Sinclair et al., 2017). Empathy is the recognition and sharing of another's feelings, initiated automatically by another's negative or positive experiences. The contemporary use of the word developed from the German "Einfühlung", or "feeling into" (Ganczarek, Hünefeldt and Belardinelli, 2018). Similarly, autopathographies illicit empathy and greater awareness toward vulnerable groups through comics' ability to use engaging visual metaphors to communicate subjective experiences (Miller, 2008; Green and Myers, 2010; El Refaie, 2014; Myers et al., 2019).

Compassion emerges from empathy and implies deliberate, other-focused and pro-social actions (Dowling, 2018; Gilbert, 2019; Hofmeyer, Kennedy and Taylor, 2020). Neuroscientific studies echo these definitions; fMRI scans show how compassion training changes participants' reactions to another's suffering by increasing positive, loving feelings and decreasing negative feelings. Empathy training, in contrast, increases negative feelings, experiences of pain and asocial behavior in the empathizer (Singer and Klimecki, 2014).

While empathy and perspective-taking are integral aspects of graphic medicine and arts-based health programs more broadly (Fancourt and Finn, 2019), caregiver empathy is associated with burnout and apathy (Garcia-Uribe and Pinto-Bustamante, 2023). Within graphic medicine, empathy may inadvertently reinforce problematic dynamics between vulnerable groups and caregivers (Godfrey-Meers, 2023). This may be because the transition from empathy into compassion is hindered by the empathizer's desire to alleviate their own distress (Vieta et al., 2024). Upon encountering another's suffering, empathizers may withdraw from or distort the other's perspective, overwhelmed by mirroring their negative emotion (Stefanello, 2022).

Several compassion trainings regulate the empathizer's distress through mindfulness meditations that stabilize attention and systematically instill a pattern of loving responses to oneself and others. A view of universal suffering, awareness of body and breath, identification with all humanity and the need for [self]compassion all underpin a range of compassion-based interventions such as Compassion Cultivation Training (CCT), Cognitively-Based Compassion Training (CBCT), Mindfulness and Self-Compassion (MSC) and Loving Kindness Meditation (LKM) (Brito-Pons, Campos and Cebolla, 2018; Ash et al., 2021; Alcaraz-Córdoba et al., 2024).

The research objective, within the context of the 2024 ESHMS conference, is to advocate for the inclusion of graphic medicine & mindfulness-based compassion training principles in care. Specifically, the co-creation of compassion comics may serve to:

promote trust, equanimity & attentiveness between participants and readers such as caregivers, care recipients, affected families and care administrators; generate insights around the empathetic distress that withdraws readers of graphic medicine from those in need; reveal nonverbal or embodied aspects of care relationships through visual metaphors; visualize and model techniques that fosters compassion in specific settings; and, lastly, synthesize co-created [auto]biographies into artistic products that can advocate for compassionate care. In conclusion, I propose that comics-making, supported by mindfulness-based compassion theories, is well-positioned to address the growing demand for subjective, qualitative frameworks that can measure and delineate empathy and compassion as a construct within institutions and relationships (Strauss et al., 2016; Vieta et al., 2024). As compassion measurements rely on self-reporting experiences to understand outcomes, the subjective experiences of caregivers and those receiving care become a significant source of insight (Mascaro et al., 2020). Compassionate comics may further contribute to the discourse on the contested notion of "compassion fatigue" in care (Dowling, 2018) and support compassion training itself during participants' visualization of compassionate frames that prime later interactions (Wilson-Mendenhall, Dunne and Davidson, 2023).

Doing research with children: Narrating illness through drawings and vignettes

Stefania Fucci (University of Parma), Anna Rosa Favretto (University of Turin), Francesca Zaltron (University of Eastern Piedmont)

Health and illness, like all areas relating to the personal and private sphere, are particularly difficult to investigate. The difficulties are amplified especially with regard to health and illness in childhood and adolescence, for a number of reasons including the different recourse of adults and children to scientific categories for the conceptualization and verbalization of illness states (Christensen, 1998; Favretto et al., 2017; Favretto & Zaltron, 2013). Moreover, today the way of understanding and experiencing states of health/illness and well-being/malaise is understood as the result of elaborations produced not only by adults, but also by children who are considered active and competent subjects in the construction of their own health and well-being paths. The recognized centrality of children urges reflections on the choice of the most appropriate methodologies with which to take their point of view also in the health field (Barker & Weller, 2003; Coyne et al., 2009; Hill, 2006).

It is therefore necessary to adopt specific investigation perspectives and non-traditional investigation tools that can bring out the children and adolescents' point of view in order to capture the multiple and different meanings they attribute to these states. Starting from our research experiences conducted with children in the field of health and illness, this contribution intends to present some critical reflections on tools such as vignettes and body mapping adopted within the so-called mosaic approach (Clark, 2004; Clark & Moss, 2011).

Vignettes, as short stories in which some fictional characters act in well-defined circumstances, make it possible to capture both individual beliefs, judgements, values and attitudes about a given phenomenon (Barter & Renold, 2000; Corser & Furnell, 1992) and the lived experiences of the subjects (Barter & Renold, 2000; Rahman, 1996). They can therefore be a useful tool for the detection and analysis of daily practices through which the children experience of illness could be captured. The concept of 'daily practice' (Reckwitz, 2002; Watson et al., 2012) seems to meet these requirements since it concerns the set of behaviors, knowledge, routines and horizons of meaning that recur in everyday life. It allows for the emergence of both the processes by which individuals, adults and children, adapt and elaborate responses to the constraints and resources of their life contexts, and the 'taken for granted' that recalls the broader system of meanings of the culture in which it is inserted.

Body mapping, a tool that involves the use of visual methods (the drawing of the whole body or a part of it) by the subjects participated in the research, can instead be used to gain access to people's perceptions of their bodies and the explanatory models they use in the course of narratives concerning experiences of health and illness. Its use in research with children is considered to be very useful in promoting subject participation and exploring the meanings attributed to health and illness.

The adoption of visual tools or tools that leave room for a visual representation that encourages not only the interaction but also the narration on the part of younger children, even with all the limitations that will be highlighted in the course of the intervention, seem to be extremely useful, especially when employed in a multi-method approach, such as the mosaic approach. The use of body mapping and vignettes within a multi-method approach responds to the need of facilitating communication between the adult researcher and the children, in an attempt to mitigate the asymmetry of power present in the settings constructed for data collection, especially when the research focuses on sensitive topics such as children's health and illness.

Cultural Sensitive Healthcare Services, Regular session – Chair: Melissa Ceuterick – Room K.102

Medical decision-making challenges among migrant populations in Belgium: A focus group study

Amina Yakhlaf (University of Antwerp), Flore Vermijs (University of Antwerp), Sarah Van de Velde (University of Antwerp), Edwin Wouters (University of Antwerp), Veerle Buffel (Free University of Brussels), Josefien Van Olmen (University of Antwerp), Paul Van Royen (University of Antwerp), Nina Van Eekert (University of Antwerp)

Medical decision making (MDM) is at the core of clinical practice and involves low- and high-stake decisions related to treatment options. This study explores the challenges faced by individuals with a migration background in Belgium's healthcare system, focusing on medical decision-making (MDM). We intend to examine two primary challenges: (1) preferences for information disclosure and (2) responsibility in MDM. In Belgian healthcare, where the law and ethical codes mandate clear disclosure of diagnoses, prognoses and perhaps therapeutic options, migrant patients often prefer limited information or truth concealment based on their collectivistic cultures. This sometimes results in favoring family involvement over direct patient communication. Additionally, these populations may prefer family-centered decision-making, contrasting with the emphasis on patient autonomy in Belgian medical practice.

Our research specifically investigated these aspects of MDM among the three largest immigrant groups in Belgium—Maghreb, Turkey, and Sub-Saharan Africa—building on four focus groups discussions (FGD's) comprising patient representatives on the one hand and healthcare workers the other.

The main goals of the FGD's was to examine the unique preferences and challenges these groups face in MDM across various contexts, including critical versus chronic care, decisions with severe versus less severe consequences, and choices concerning physical versus mental health disorders. Secondly, we aimed to examine the strategies physicians have developed to address these preferences and challenges.

Preliminary findings reveal considerable preferences and challenges within these three migrant groups, varying based on the medical situation from both patient's and healthcare worker's perspective.

A thematic analysis of the focus group discussions with patient representatives revealed significant difficulties based on certain medical situations on patients perspective. Challenges and preferences were particularly apparent in mental health issues, sexual health, end-of-life care, pain management, and urgent surgical decisions. Other factors influencing the medical decision making process of people with a non-European migration background included language barriers, socio-economic status, the duration of residence in Belgium, gender considerations and religious affiliations.

The FGDs conducted with General Practitioners (GPs) revealed that preferences and difficulties were significantly pronounced in the domains of chronic diseases, mental health issues, diverse perspectives on palliative care, preferences regarding contraceptives, considerations pertaining to dental care, and illnesses associated with labor or work. These results offer valuable insights into the nuanced complexities inherent in these thematic areas.

This dual-pronged approach, involving both patient and healthcare provider perspectives, enriches our understanding of the complex dynamics surrounding medical decision-making in the multicultural landscape of Belgium's healthcare system. This study underscores the importance of culturally sensitive healthcare practices to address the diverse needs of migrant populations in medical decision-making processes, emphasizing the evident need for more extensive research within a representative sample to systematically document preferences.

We will build upon the current findings in the following phases, aiming to conduct a comprehensive qualitative and quantitative survey in Flanders.

Integrating culturally sensitive healthcare practices is crucial not only for understanding the diverse needs of migrant populations but also for fostering effective communication and tools regarding decision-making processes, ultimately enhancing the quality and equity of healthcare services in Belgium.

Facilitators and barriers to the implementation of multicultural competence training programs for healthcare staff and students

Beatriz Xavier (Nursing School of Coimbra), Ana Paula Camarneiro (Nursing School of Coimbra), Filipa Ventura (Nursing School of Coimbra), Aliete Cunha Oliveira (Nursing School of Coimbra), Ana Paula Monteiro (Nursing School of Coimbra)

Introduction

Cultural competence training for healthcare professionals is an imperative challenge in today's culturally diverse societies to ensure that all people receive equitable and effective health care, particularly those from culturally diverse backgrounds. There is a global need for good-quality, robust and resilient health services that are culturally and linguistically sensitive and that can respond to the needs of refugees and migrants. Health services should be provided with an adaptable, well-trained and culturally competent workforce (WHO, 2020, p.5). Therefore, as point out by A. Kleinman and P. Benson (2016), there has been an effort to teach "cultural competence" to health care providers, however, there is little evidence that such training programs work.

Methodology

A scoping review was carried out with the aim of identify training programs in multicultural competencies for health care staff and health students in professional and academic settings (Teixeira-Santos et al., 2022).

From the 179 included articles, 71 reported on educational programs for training on cultural competence of healthcare professionals underpinned on theoretical models. The facilitators and the barriers of the implementation of the programs as reported in these studies were identify. 31 studies elicited facilitators and 32 studies elicited barriers in the process of implementing the strategies of education or training of programs in cultural competences.

Results

The following facilitators and barriers were identified: a) Preparation and capacities of trainers and institution. Trainers are central actors in the success of the programs. Equally important is the participation of faculties with high interest and commitment to the subject in all disciplines and training sessions for faculty members to develop prior preparation. In some studies, the participants perceived it as an advantage that the training was not provided by their own healthcare organization or by a healthcare professional. They stated that bringing new perspectives and ideas to the hospital environment from outside the healthcare field could facilitate the development of cross-cultural care. The possibility to learn foreign languages in the curriculum is also valued. b) Implementation of training. The use of technological solutions is pointed out as a facilitator for the implementation of programs. Studies underline as positive that courses use active methods and are easy to apply in a classroom environment. There are positive experiences with virtual communication. It seems consensual that learning is emphasized when students interact. Immersion situations in real-world contexts are highly valued. Students participating in immersion activities feel more competent to work with language barriers, recognize differences in health systems, have greater openness to individual differences. Simulated learning has been shown to be beneficial. c) The barriers pointed out to the implementation of educational programs occurred at the level of training implementation (i.e. organizational contexts, technical difficulties, and training evaluation), and at the level of students and trainers. Some contexts were systemically resistant to change and with reduced resources allocated to specialist services that support ethnic and minority patients. Such

characteristics will impact on both the uptake of training and learning processes. Technical difficulties are also very relevant, such as the use of video link-up related to internet connectivity, hardware, and software compatibility. Evaluating the program's content is also highly challenging. Implementing new cultural approaches, ideas, and initiatives in one's department was described as more difficult if colleagues had not also participated in multicultural competences programs.

Conclusion

The authors emphasize that it is important for students to understand their own culture including concepts such as prejudice and stereotype and that it is more significant to understand the importance of individualized care combined with the implementation, understanding and appreciation of cultural facts in context.

Adopting multiple perspectives through the participation of professionals from different fields or organizations should be considered. Broader and dynamic understanding of culture could also help debunk the prevailing notion that cultural competence skills only apply to the care of the 'other' rather than to the assessment and treatment of all persons.

Students had difficulties in detaching themselves from the busy clinical settings. Results also indicate that it can be difficult to arrange enough time in healthcare for this type of training and, therefore, learning possibilities that are not bound to an exact time or place need to be further developed. To assist the development of competencies in the cultural domain, the evidence on teaching and training strategies point to the need and value of innovative pedagogical approaches to capture students' attention, prompt engagement and challenge their self-horizons. The importance of the presence of non-medical trainers in these courses is emphasized.

Bedside transformations: Doctor becomes patient

Hannah Bradby (Uppsala University)

Introduction

Effective healthcare depends upon biomedical and clinical expertise operating alongside other types of practical, existential and experiential knowledge. Working with doctors who have also been patients, this project seeks to access how they bring together their clinical expertise and knowledge to understand and process the experience of illness, treatment and recovery. Professionals with expert understanding of bodily pathology, its medical treatment and the healthcare system which delivers that treatment, who have also been subject to such treatment, can offer insight into the difference that makes a difference during healthcare encounters.

Methodology

This paper reviews published biographical accounts of doctors who have become ill, required treatment and reflected over their experience. In particular, the review selects for indications of different forms of knowledge being deployed; when epistemological clashes and / or multiple interpretations of the same interactions are apparent. The mapping of gaps and overlaps in different forms of understanding in play is the aim of this analysis.

Results

Doctors who have been patients, represent a valuable resource for service improvement because of their access to medical and clinical knowledge as well as embodied and existential experiential knowledge. By mapping professionals' experience of suffering and identifying the moments where medical treatment compounds suffering rather than promoting recovery, we can identify the limits of biomedical models of care and integrate alternative forms of experiential and embodied knowledge without jettisoning medical expertise. By attending to the moments where epistemological understandings are successfully synthesized, to the satisfaction of the patient-doctor, we may be able to define attributes of good healthcare interactions.

Conclusion

We offer evidence of multiple epistemological understandings of healthcare encounters that doctors who become patients report and consider how these can be applied in terms of service improvement.

Why we need to change the narrative on ‘FGM’

Saffron Karlsen (University of Bristol), Natasha Carver (University of Bristol), Magda Mogilnicka (University of Bristol), Christina Pantazis (University of Bristol)

Introduction

Female genital cutting or ‘mutilation’ (FGC/M) is internationally regarded both as a health and a human rights issue. Global prevalence estimates suggest that over 200 million women and girls have experienced forms of medically unnecessary genital cutting, excluding those with elective genital “cosmetic” surgery. The increasing migration of people from countries with higher rates of FGC/M to lower prevalence countries, such as those in Europe, has prompted efforts among health professionals and policy makers to understand and reduce the ongoing risk for women and girls with heritage in those communities.

Political and media discourse suggests that around 60,000 young girls living in the UK may be at risk of FGC/M, based on figures derived from applying prevalence rates from ‘high’ FGC/M prevalence countries to the numbers of girls born to women from those countries living in the UK. Despite growing concerns regarding the problems of this guesstimate, the belief that tens of thousands are at risk has led to the introduction of a series of punitive legislative and policy measures including, since 2015, mandatory reporting for health professionals, as well as specific data collection in medical settings: a pattern of criminalization repeated elsewhere in Europe. This presentation analyzes the likely risk of FGC/M to girls living in the UK, and also the direct and indirect harm caused by these policies to intersectional and inclusive healthcare.

Methodology

This presentation draws on a program of research by Bristol Research on Female Genital Modifications. These include: an analysis of UK-focused quantitative data including NHS Digital’s publicly-available ‘FGM Enhanced Dataset’ and data accessed via Freedom of Information requests to the Home Office, Department for Education and Ministry of Justice; and qualitative data from a 2018 focus group study with people of Somali heritage living regarding their experiences of FGM-safeguarding, and a 2022 mixed-settings study with men and women from multiple ‘high-prevalence’ countries exploring the care needs of those living with the long-term health and other consequences of FGC/M and their management within healthcare settings, both conducted in Bristol.

Results

Our research identifies significant limitations to the value of UK-based sources for establishing FGC/M risk (Karlsen et al 2023). These include issues with record retention and coverage, with most data collected from adult women attending maternity clinics with historical experiences of FGC/M. Despite these issues, these data indicate that the number of girls and young women living in the UK and at risk of FGC/M is far below that typically assumed, with numbers likely to be in the hundreds (or less) rather than tens of thousands. The focus groups reinforce these conclusions, indicating low levels of support for FGC/M among ‘migrant’ groups in large part due to the effectiveness of community-led education campaigns.

Our research also illustrates the significant harm inadvertently caused by these policies to women living with FGC/M, their children, families and communities (Karlsen et al 2019, Carver et al 2022). Whilst well-intentioned, data collection for the FGM Enhanced Dataset retraumatizes women and undermines their receipt of inclusive and effective healthcare, with participants describing a loss of trust in and disengagement from healthcare as well as a greater sense of social exclusion as a direct consequence of these experiences.

As well as the direct harmful effects of these policies, our research highlights the ways in which this policy focus on criminalization causes indirect harm as a consequence of the care poverty experienced by those living with the long-term physical, mental and sexual health consequences of FGC/M (Pantazis et al 2023). Current FGM-safeguarding policy is premised on the significant harm caused by (some forms of) FGC/M, yet its focus on prevention frames those with prior experience of FGC/M only as potential perpetrators. As well as directly undermining familial bonds (Karlsen et al 2019), this approach ironically ignores the health needs it is seeking to protect others from.

Conclusion

There is a dire need to change the narrative on 'FGM' in the UK, and elsewhere in Europe. Framing those with lived experience as partners rather than perpetrators will enable us to realize opportunities to co-develop inclusive and intersectional approaches to healthcare which can reduce the harmful consequences of existing approaches to FGM-safeguarding while ensuring that the (other) health needs of people living with the consequences of FGC/M are more effectively addressed.

Variety in caregivers' views regarding care responsibilities from an intersectional perspective

Yvette Wittenberg (University of Amsterdam; Amsterdam University of Applied Sciences), Rick Kwekkeboom (Amsterdam University of Applied Sciences), Alice de Boer (The Netherlands Institute for Social Research), Arnoud Verhoeff (University of Amsterdam)

Introduction

Like other European countries, the Netherlands faces significant challenges in how to enable good care and support in the coming years due to ageing, increasing care needs and workforce shortages in the healthcare sector (den Broeder et al., 2023). To meet the increasing demand for care, Dutch authorities are trying to shift (more) care responsibilities from formal to informal care (Duijs, 2023). This makes informal care increasingly important and therefore understanding the attitudes of people who provide informal care is essential (Wittenberg et al., 2021; Zarzycki et al., 2022). Such care attitudes encompass opinions regarding the division of care responsibilities between family and/or social networks and the state. As care attitudes are shaped by value patterns within groups individuals belong to (Dykstra & Fokkema, 2012), an imperative question is the extent to which informal caregivers differ in their care attitudes. Insight in these differences can help policy makers and social and healthcare professionals in meeting a wide variety of expectations from informal caregivers (Quashie et al., 2022). During the study, an intersectional approach was adopted to be able to move beyond single social positions such as gender, age, and socioeconomic status, and thus highlight the multi-dimensional and relational nature of informal caregiving and the social conditions within which informal care is provided (Crenshaw, 1989; Hankivsky, 2014).

Methodology

In this qualitative study, 37 individual interviews and eight focus groups were conducted to investigate how Dutch caregivers' care attitudes are shaped by their social positions (Wittenberg et al., under review). Participants had to provide informal care to someone they know, regardless of the care demands the care recipient faced. To be able to consider caregivers' social positions in relation to their care attitudes, all participants were interviewed individually prior to the focus groups they attended. After that, eight focus groups were conducted to elaborate on informal caregivers' care attitudes and how care attitudes are shaped. All interviews and focus groups were recorded and transcribed verbatim, after which qualitative content analysis was conducted (Hsieh & Shannon, 2005).

Results

This study shows that many caregivers want to assist their loved ones themselves and feel a moral obligation to do so, but at the same time, they also expect the government to play a role in caring for those in need (Wittenberg et al., under review). Caregivers expect the government to ensure professional care is accessible, affordable, and

facilitated. Results also show caregivers' intersecting social positions, such as gender, migration background, socioeconomic status, and stage of life, largely influence their care attitudes. This conforms that intersecting mechanisms of inequality such as gender and migration background can account for an asymmetric distribution of care tasks (Tronto, 2013). Using intersectionality brought forward other, possibly less obvious, interactions with social positions as well. For example, when cultural backgrounds influence how informal caregivers think about providing informal care, this can intersect with upbringing, family ties, or religiosity.

Conclusion

Informal caregivers' social positions mutually influence the way they think about the division of care responsibilities. Although many informal caregivers can and want to do a lot for their loved ones in need, they believe this should not become an obligation imposed by the government. Professionals should invest in getting to know informal caregivers and their unique circumstances as this creates understanding about what caregivers can and want to do in specific care situations. Professionals and policy makers should be careful not to homogenize groups of informal caregivers based on (some of) their social positions, as informal caregivers have different care attitudes, experiences, and needs.

Health Behaviors and Lifestyle, Regular session – Chair: Thomas Abel – Room K.103

Risky Leadership and Health-Risk Behavior in Adolescence

Galya Chamova (Trakia University), Georgi Sarov (Trakia University)

Introduction

Risky behavior during adolescence serves as a significant predictor of chronic diseases in adulthood, believed to be strongly socially motivated (Gittelsohn et al., 2001). However, the social determination of risky behavior remains somewhat elusive, seemingly legitimate within certain sociological or psychological contexts, lacking formal legality. While Bandura's social-cognitive approach (1989) facilitates an explanation in terms of behavioral coping, it falls short of clarifying why health-harming behaviors evolve into role models. In our investigations, we have uncovered data that may shed light on this question.

Methodology

We conducted a cross-sectional study on alcohol consumption, tobacco smoking, and drug use among 903 adolescents, equally represented in both sexes. The study utilized an original questionnaire for anonymous self-assessment of risk behavior. The sample was categorized based on the intensity of risky behavior concerning tobacco smoking (heavy smokers (HS) and non-smokers (NS); Sarov, 2010) and alcohol consumption (regular (RD) and social drinkers (SD), and abstainers (ND); Chamova, 2016). Data analysis employed descriptive statistics and logistic regression. Constructive analytical techniques were used to identify significant differences and provide a coherent interpretation of the empirical results.

Results

Our analysis focuses on three data clusters: Statistical analyses reveal that, in the presence of peers, RD individuals are 8.53 times more likely than ND individuals to initiate alcohol consumption for the first time, 2.36 times more likely to initiate smoking, and 2.59 times more likely to initiate drug use. The declared motive is "to alleviate cohesion with peers." Similarly, HS individuals are 4 times more likely to start drinking and 5 times more likely to initiate drug use than NS individuals. This evidence suggests that risky behaviors symbolize and contribute to social integrity, at least in the adolescents' imagination and social practice.

Party appears to be a powerful stimulus for intensifying risky consumption. SD individuals are 1.78 times more likely to drink more at parties than ND individuals (and RD individuals are 2.63 times more likely than SD individuals). RD and SD individuals are 2.69 and 2.12 times more likely, respectively, to increase smoking at parties (compared to ND individuals). RD individuals are 4.68 times more likely to initiate and 3.79 times more

likely to increase drug use compared to SD individuals. HS individuals are about 3 times more likely to start and 11 times more likely to increase drug use during parties. It appears that RD individuals are more strongly motivated to initiate and increase their risky behaviors at parties than SD individuals, and later are more motivated than ND individuals. HS individuals are not more motivated to drink and smoke, but to use drugs. It seems that proving the prestige of being risk-taking persons motivates RD and HS individuals to become even more risk-taking at parties.

HS and RD individuals are much more sexually active than NS and ND individuals, respectively. HS individuals are 2.18 times more likely, and RD individuals are 2.51 times more likely to declare having satisfied sexual relations. HS individuals are 2 times more likely, and RD individuals are 4.38 times more likely to declare regular sexual experiences. HS individuals are 2.33 times more likely, and RD individuals are 7.06 times more likely to have had more than 5 sex partners until the moment of inquiry. HS individuals are 2 times more likely, and RD individuals are 2.26 times more likely to think about sex, with RD individuals being 3.13 times more likely to be sexually initiated at parties. The sexual context seems to be more arousing and more strongly motivating HS and RD individuals' behavior than in abstainers.

Critical analysis indicates that the three clusters of significant differences can find a unified social explanation in the sexual context: adolescence places sex as an exclusively important aspect of life, social image, and self-construction, thereby triggering a drive for dominance and need of attention. Risky behaviors become part of a charismatic risk-taking style, fostering curiosity and sense of inferiority among others. In a social context, only dominant individuals receive the privilege of being sexually attractive, arousing the opposite sex. Striving for sex implies striving for dominance at any cost, and the excessive risk behavior is a way to stand out from others in an undeniable way.

Conclusion

It is well-known that membership in adolescent groups strongly correlates with risky behavior (Dolcini & Adler, 1994), and sexual motives play a crucial role (Ohene et al., 2005). Our data not only validate these suggestions but also introduce a novel dimension: a potent desire for dominance over the crowd appears to be a catalyst for heightened levels of smoking, drinking, and drug use. As a part of charismatic risk-taking personality, the demonstrative and excessive health challenging may serve as a way for positioning in the center of attention of others and gaining respect and sexual attraction to alleviate sexual intercourse. So, we propose the term "risky leadership" for this personal motive for gaining social dominance and sexual attractiveness via excessive health risky behaviors.

An intersectional approach towards accelerometer-based physical activity and sedentary behavior patterns in children

Mari Sone (Amsterdam UMC), Teatske Altenburg (Amsterdam UMC), Lauren Sherar (Loughborough University), Dale Esliger (Loughborough University), Mai ChinAPaw (Amsterdam UMC)

Introduction

A growing body of research has shown inequalities in the amount of physical activity (PA) among children based on gender, ethnicity, and social class. However, few studies have focused on the intersections of such characteristics and how these are related to PA. A pressing call within the academic community emphasizes the need for increased research efforts dedicated to quantitative intersectional analysis in the domain of PA (Lee et al., 2023)

Traditional analyzes of movement behaviors have predominantly examined summary metrics of either PA or sedentary behavior (SB), such as the total amount of moderate to vigorous intensity physical activity (MVPA) per day. This conventional approach, while informative, tends to oversimplify the multifaceted reality of PA, neglecting critical nuances such as accumulation patterns of SB and PA. For instance, the same 60 minutes of

MVPA per day can be accumulated in diverse profiles, ranging from a continuous 60-minute session to 20 brief (3-minute) sessions. Similarly, individuals with identical MVPA levels can engage in very different sedentary behavior (SB) and light PA patterns.

In response to these limitations, ChinAPaw et al. (2019) developed a sequence mapping analysis method, aiming to comprehensively consider both the duration and frequency of all intensities ranging from SB to vigorous intensity PA, resulting in a 'sequence map' of an entire day or week. The objectives of this study are to explore (i) how children's PA and SB patterns (analyzed as sequence maps) vary between intersectional subgroups based on the combination of gender, ethnicity, and parental education level, and (ii) how these behavioral patterns are associated with health indicators.

Methods

For this study, we will use the International Children's Accelerometry Database (ICAD), a repository harmonizing accelerometer studies on children across the globe (Sherar et al., 2011). To eliminate country-specific context behind disparities, we will focus on UK-based datasets: Children's Health Activity Motor Program (CHAMP) UK, the Avon Longitudinal Study of Parents and Children (ALSPAC), and Personal and Environmental Associations with Children's Health (PEACH UK). These datasets include children (n = 7854 in total) aged between 10 and 17 years and the data collection spanned between 2003 and 2009. Across the studies, participants were asked to wear an ActiGraph accelerometer (ActiGraph, FL, USA) on their right hip during waking hours for seven days, except for water-based activities.

We will produce a sequence map spanning three school days for each child, taking into account how children accumulate and alternate different intensities ranging from SB to vigorous intensity PA. Subsequently, a multi-level hierarchical cluster analysis will be deployed to discern distinct groups of children sharing similar behavioral patterns. The cluster analysis will be conducted within two types of subgroups, 1) based on gender, ethnicity, or parental education levels separately, and 2) intersectional subgroups, based on combinations of gender, ethnicity, and parental education levels.

Additionally, our investigation will examine differences in health indicators across the intersectional subgroups. This includes waist circumference, blood pressure, and high-density and low-density lipoprotein cholesterol, triglycerides, glucose, and insulin levels assessed in fasting blood samples. Regarding the health indicators, categorical variables will be analyzed using chi-square tests and continuous variables using analysis of variance (ANOVA).

Results

The data resulting from the intersectional approach towards sequence mapping will be presented at the conference.

Conclusions

This study will provide relevant insights in the accumulated movement behavioral patterns in intersectional subgroups.

How people living with traumatic brain injury experience biomedicine and complementary and alternative medicines

Peta S. Cook (University of Tasmania), Ashleigh Barnes (University of Tasmania)

Introduction

Traumatic brain injury (TBI) results from an external assault to the head that creates trauma and disrupts regular brain function. This can be caused by being hit by a vehicle or through interpersonal violence, injuries related to alcohol and drugs, and military service. For some people, recovery from TBI is possible but, for others, they may

experience a range of long-term or lifelong symptoms that impact their cognitive, physical, behavioral, and emotional regulation. Despite these factors, TBI continues to be medically framed as an acute event, with diagnostic and treatment pathways being inconsistent and vague. For those experiencing long-term symptoms, living with TBI means a continuing to seek help and advice in managing symptomology throughout their life, which may include using complementary and alternative medicines (CAMs).

Methodology

To understand people's lived experiences of TBI, we recruited people with a diagnosis of TBI (mild to severe cases, as well as suspected and diagnosed post-concussive syndrome), and their carers or family members. In total, 27 interviews were conducted with people living across Australia. The average interview length was 60 minutes. All interviews were transcribed verbatim and both authors used thematic analysis to identify themes from the data. In this presentation, we draw attention to one theme emergent from this analysis: relationships with biomedical model. Our research project received ethics approval from the University of Tasmania Human Research Ethics Committee.

Results

In examining the relationships our participants have with the biomedical model, our analysis revealed two important aspects: experiences with biomedicine, and experiences with CAMs. In their experiences with biomedicine, our participants noted that a range of health providers were dismissive of their TBI symptoms, or unhelpful or unskilled in ongoing symptom management including providing advice on treatment pathways. Regarding participant experiences with CAMs, this did not occur as a rejection of biomedicine. Rather, participants told of negotiating a balance of biomedicine with CAM, or leaning into CAM when guidance from healthcare providers was ineffective. Referral pathways to CAMs came from formal recommendations by doctors, though often occurred through family and friends. The utilization of a diverse range of medical and non-medical supports shows how living with TBI is an active, ongoing, and pluralistic process.

Conclusion

Our findings illustrate the challenges that people living with TBI experience in trying to seek recognition, support, and assistance in ongoing symptomology and symptom management, and how gaps in biomedicine lead or force them to pursue other healthcare options including CAMs. This exposes inherent complexities with relying on and resisting biomedicine for managing chronic illness and disability after acquiring a TBI. Furthermore, this reveals that people living with TBI are not active or passive consumers of biomedicine or CAMs. Rather, the gaps within the biomedical model have led our participants to explore other options and pathways to help manage their symptoms and achieve wellbeing; they are pursuing a range of options that best suit them and recognize or support their lived experiences with TBI. Our findings thus indicate how biomedicine is failing to support and recognize the ongoing impacts of TBI for those who live with it, while also revealing that sociological arguments that position CAM users as either empowered or disempowered may overlooks the nuances experienced by those living with chronic illness and disability.

Doing intersectionality through co-production: Addressing inequalities in physical activity and health for disabled people

Toni Williams (Durham University)

Introduction

The negative impact of physical inactivity on health is exacerbated by the inequalities experienced by disabled people, especially those with intersecting marginalized identities. Intersectionality examines the relationship between numerous interlocking systems of oppression, and is well placed to explain why unequal opportunities and participation in physical activity continue to exist for disabled people who experience multiple forms of discrimination (Richard et al., 2023). Yet, few research studies have taken an intersectional approach to explore this issue.

Methodology

Adopting a method of participatory co-production, we sought to advance our knowledge and understanding of the needs and priorities of disabled people with intersecting marginalized identities in relation to physical activity and health inequalities. To meet this aim, we collaborated with Disability Rights UK (DRUK) – the UK’s leading organization led by, run by, and working for disabled people – to create the Moving Intersectionality co-production group. Comprised of disabled people from diverse backgrounds, we are working together to address inequalities and promote social justice in relation to physical activity and health.

Drawing upon this project, the aim of this methodological presentation is to examine how to ‘do’ intersectional co-production through the integration of equitable and experientially-informed co-production, and intersectionality methodology. Equitable and experientially-informed co-production, differs from other methods of co-production, by positioning people with lived experience and experiential knowledge as essential to the research process through equitable research partnerships (Smith et al., 2023). Yet, to ensure our co-produced research addressed the needs and priorities of disabled people experiencing multiple forms of oppression, we applied the guiding principles of intersectionality methodology.

Haynes et al. (2020) derived the term intersectionality methodology through a review of empirical studies about Black women in higher education to explore how Crenshaw’s (1989, 1991) three-dimensional (e.g., structural, political and representational) intersectionality framework had been employed methodologically in the past 30 years. Intersectionality methodology arose from analysis of the application of these three dimensions of intersectionality, and resulted in four features to guide decisions scholars make about study design, methods and analysis. These features are: centering Black women as the subject; using a critical yet intersectional lens to examine micro/macro-level power relations; addressing power in the research process; and bringing complex identity markers to the fore.

Results

We build upon our experiences captured throughout the Moving Intersectionality project through interviews, reflective diaries and meetings, to illustrate the challenges we faced in co-production and how we overcame them. This includes how we set up our principle values at the start of the project and ensured we were adhering to them. These principles were informed by both equitable and experientially-informed co-production and guiding features of intersectionality methodology. For example, one feature of intersectionality methodology identified by Haynes et al. (2020) addresses power in the research process to engage political intersectionality. Here, critical reflection of positionality is necessary to address power and how research practices privilege certain voices and silence others. Addressing power is of equal importance in equitable and experientially-informed co-produced research. Smith et al. (2023) note that equitable partnerships with community and citizen partners can only be formed by addressing oppressive structures, systems and hierarchies in power to illustrate how they have marginalized certain people and forms of knowledge.

As such, our principles comprised: calling in rather than calling out in co-production meetings to bring attention to any harmful words or behavior including bias, prejudice, microaggressions, and discrimination; sharing power with partners with lived experience through influencing decision-making throughout the research process; and creating appropriate and inclusive spaces for different knowledge bases and contributions to be respected, valued and blended. For this presentation, we reflect upon ‘how’ the Moving Intersectionality co-production group had the power to inform the research priorities that were important to them, using methods of data collection and analysis that were meaningful to them, and devised their own strategies to put research evidence into physical activity practice and policy. We also consider how decision-making was managed, how we negotiated conflict, our considered use of language, and how assumptions, privilege, and lived experience influenced the research.

Conclusion

We conclude with theoretical and practical recommendations to support how intersectional co-production can be done to address inequalities and limitations in social justice in physical activity and health.

Intersectionality and agency in the sick role

Weiwei Lu (City University of Hong Kong)

Introduction

From the sick role to health service consumer, ill people are granted with various social roles according to the dominant discourses in different times and contexts to meet expectations of the society. However, the agency of patient behavior to perform the social role as a patient is still a myth.

In the classic sick role theory proposed by Talcott Parsons since 1951, ill people have been regarded as deviant conditions from the society and play the social role of the sick role without productivity (Parsons, 1951).

Levine and Kozloff (1978) reviewed over 100 books and articles and found that researchers during 1960s-1970s, no matter the critics and supporters, attempted to test Parsons's formulations. Thus, agency in the sick role mainly refers to patients' motivation to adopt the sick role and their strategies to adapt to the sick role (Levine & Kozloff, 1978).

However, since 1980s, it is found that the research with the underlying structural – functional perspective neglected the role negotiation and conflicts during the socialization of patient. Stewart and Sullivan (1982) claimed that there is a role negotiation process in the therapeutic encounter which is shaped by both the interaction in the situation and the normative expectations of the society (Stewart & Sullivan, 1982). By observing 35hrs' reactions between staff and patients, the researcher found there are three types of patient behavior causing role conflicts (Hall, 1975). Moreover, Waitzkin (1971) found the sick role could mitigate the disruptive conflicts between personality needs and the social system's role demands by functioning in the multiple institutions of family, hospital, state, and other relevant systems (Waitzkin, 1971).

Framework

Being aware of the multiplicity and intersection of social roles embedded in a patient position, we need to take an ontological shift to understand the socialization of patient.

Under the social constructionism, particularly the narrative perspective, the meaning of illness is interpreted from different contexts. Ill people will perform different social roles in those narratives. Each narrative stands for a social order to involve ill people in reproducing that social structure to maintain productivity.

Facing the multiple narratives, the agency of performing a patient role is more about decision making among the multiple subjective interpretations of illness to meet social expectations. The choice of a social role means a choice of a dominant narrative. In this way, ill people become a narrative subject who can present a temporal process including the stages of changes and the agency behind the changes in an illness career (Goffman, 1961). As a narrative subject, ill people carry many narratives and corresponding identities in their discursive expression and behavior.

Therefore, this study aims to explore: What are the dominant narratives and social roles embedded in cancer patients? How do they deal with the multiple narratives of illness and treatment and their multiple social roles? How did they make decisions in adapting to or resist a social role?

Methods

This study adopted an ethnography informed method. 32 cancer patients from a hospital in Northwestern China were observed and interviewed by the author. They were invited to share their experiences in seeking professional help, discussing diagnosis, selecting treatment, and complete treatment. They were also asked

about the obstacles in their cancer treatment process and the motivation to proceed with the treatment. A thematic analysis was applied.

Results

Three themes of results will be presented: The dominant narratives of the cancer patients; Main struggles among multiple social roles; Agency from preferred identities to perform a patient role. Though the dominant narratives, main struggles and preferred identities in this study represent culturally sensitive contents, the themes are universally applicable findings.

Performing a patient role doesn't mean they accept the identity of patient who is losing part of ability and dignity to live and decide independently. The agency of these behaviors is from the preferred identity attached to the patient role. Preferred identities are context specific thus fluid. Physicians play an important role in constructing patients' preferred identities to engage in a patient role.

Conclusion

From the sick role to a narrative subject, the socialization of patient evolved from a static expectation on the illness behavior to a dynamic interpretation and construction of illness and illness behavior. Shifted from structuralism to social constructionism, ill people perform their patient roles to meet the multiple social expectations in the society. The source of the agency to demonstrate the patient role is from the preferred identity. This study also implicates that in the medical context, we should treat patient as a person in multiple social systems. Understanding their life situations and narrative contexts and helping them construct preferred identities will improve their agency in collaborating with health professionals.

Gender and Health, Regular session – Chair: Piet Bracke – Room K.201

Inequalities in Male and Female Diabetes Mortality between Microregions in Hungary

Katalin Kovács (Hungarian Demographic Research Institute), Zsófia Kollányi (ELTE Eötvös Lóránd University), Kitti Susovits (National Institute of Pharmacy and Nutrition Budapest), Lajos Bálint (Hungarian Demographic Research Institute)

Introduction

The number of registered people living with diabetes has tripled in Hungary during the last two decades reaching the number of 1 100 000 out of the 9 600 000 inhabitants by 2021. The dynamic rise in the number of patients provoked the development of a new specialized network within the outpatient services. Former analysis of health care, in general, demonstrated high geographic inequalities in health care provision in Hungary, providing much less for those who lived far from hospitals, typically the residents of small villages. Equitableness of a newly and in some sense spontaneously formulated network therefore in itself deserves attention.

Diabetes mortality is known to be patterned by the level of social deprivation, but in one of our earlier studies, we found that traditionally used deprivation measures were not well applicable for explaining spatial mortality differences. According to our results, regional inequalities in diabetes mortality were mostly associated with the intensity of provided services in a large sense (such as nurseries, bank automats, and cultural facilities) and especially the density of grocery stores.

In this earlier analysis, we examined the inequalities in diabetes mortality across the 197 micro-regions of Hungary for two time periods: 2009–12 and 2013–16. We found large differences in mortality by some measures of health care provision (like availability of general practitioners or pharmacy), but these differences disappeared, when we took into account the general characteristics of the micro-regions, like educational level, wealth, and deprivation, in its newly defined form.

This analysis was complemented by interviews conducted between 2019 and 2023 with people living with diabetes. In the interviews, while we were originally interested in the perceived quality of diabetes care, our respondents emphasized the problem of having an appropriate diet. Women were more concerned about the questions of diet. Additionally, regional mortality differences patterned somewhat differently for men and women. Therefore we decided to run the analysis separately for men and women.

Several events suggested that the investigation must be extended also in time. First, the analysis of the mortality patterns of the COVID-19 pandemic years revealed that cause-specific mortality has increased only for two groups of diseases: diabetes and chronic kidney disease. Furthermore, in 2022, an extremely high food price inflation hit Hungary, leading to doubling food prices and the bankruptcy of many small food shops. The rise in salaries and social transfers was not parallel. In interviews of the year 2023 people living with diabetes expressed their growing despair regarding getting appropriate food.

Objective

The study of which results can be presented is aimed to find an association between the markers of socio-economic development, the markers of health care provision, and male and female diabetes mortality of the 197 micro-regions of Hungary, for the period 2009-12 and 2013-16. In another ongoing investigation, the same associations will be examined for the periods 2017-2020 and 2021-23.

Methods

The study used mixed methods. First, the relationship between socioeconomic standing and health care provision in the area and mortality was examined by several OLS regression models. Among the independent variables educational level, economic prosperity, and re-conceptualized deprivation were considered. Alcohol-related mortality served as a proxy for alcohol consumption and BMI was also included.

As health care provision, markers of the availability of general practitioners, pharmacies, the presence of specialized hospital beds within the micro-regions, the hours provided in specialized outpatient services, and quality of care indicators (type of prescribed medications, leg examination) were included in our models. From our 80 interviews, we analyzed interviews of 10 males and 10 females with the longest history of the disease and living in settlements with different service provision. We used an inductive thematic approach to identify the major themes that were important for our respondents. 3 independent researchers analyzed the transcripts and agreed on the classification of the issues.

Results

In the first period studied strong association was found between economic prosperity, alcohol consumption, and male diabetes mortality. As female mortality, is associated at the same extent with economic prosperity and alcohol consumption, but more strongly with scarcity of services, and especially with scarcity of grocery stores. In the second period, both male and female mortality was associated with alcohol consumption and scarcity of grocery stores. Female diabetes mortality was further associated with low educational level and less economic prosperity of the area.

Differences in health care provision disappeared between micro-regions, but less regarding the relative new diabetic care network, but rather in terms of primary care and access to pharmacies. Lacking general practitioner care in the settlement and pharmacy, however, was strongly associated with a wider deprivation of living in a service desert.

In the interviews, women expressed greater concern about weight control and the quality of diet. In interviews taken earlier, the personalized nature of the required diet was emphasized, while in interviews taken this year, the price of food and availability of appropriate food was the major concern. The beleaguered aspect of care was that provided (or missed) by dietitians, mentioned especially by women.

Conclusion

Contrary to our expectations, inequalities in diabetes care provision were not associated with inequalities in mortality. Weaknesses of food provision were a stronger predictor of female than male diabetes mortality in small area level in Hungary. Targeted assistance for access to healthy food is much needed. The improvement of the counselling provided by dietitians would improve disease management and reduce the medicalized nature of diabetes care in Hungary.

Scripting endometriosis: Constructing the disease and the patient in medical discourses

Nicole Braidà (University of Turin), Raffaella Ferrero Camoletto (University Turin)

Introduction

According to the most recent clinical definitions, endometriosis is a chronic inflammatory disease characterized by the presence of endometrial-like tissue outside the uterine cavity. It is estimated that approximately 10% of AFAB (assigned female sex at birth) people worldwide of reproductive age (at least 190 million people) are affected by endometriosis. Besides, some may suffer from it beyond menopause. A diagnostic delay is estimated to be between 8 and 12 years (Zondervan et al. 2020; Chen et al. 2023).

Along with other pathologies such as vulvodynia and pudendal neuropathy, endometriosis is referred to as an “invisible illness”, i.e. one of those chronic diseases that affect millions of people but do not present manifestations that are easily identifiable in organic symptoms and signals. For this reason, they have a considerable diagnostic delay in medical practice and little recognition by the State. They present highly subjective clinical manifestations and are characterized by the absence of a known aetiology and a definitive treatment, by the subjective variability of the solutions proposed to control the symptoms and by poor medical knowledge (Hawkey et al. 2022; Kaler 2006). Recently, the commitment of online and offline activism has meant that knowledge about these diseases is reaching a wider audience (Buonaguidi & Perin 2023), and has gained public recognition in some countries, for example in Italy in terms of LEA (i.e. Essential Levels of Care), although limited to the most serious stages of the disease.

The paper aims to analyze the construction of the definition of the disease, of the average/ideal-typical patient and of the therapeutic approach in medical experts’ discourse, identifying gendered scripts and normative assumptions on sexual health. Besides, it aims to reflect on how these constructions can complicate access to diagnosis and treatment for some groups of patients (e.g. people with limited economic and/or cultural resources, with a migratory background, trans and non-binary people, and people close to menopause).

Methodology

We adopted sexual script theory (Simon and Gagnon 2003) as an analytical frame to explore the cultural resources embedded in medical discourse on endometriosis. The paper is based on a recent research project carried out in Northern-Western Italy. Medical discourses on endometriosis were investigated through documentary analysis of handbooks and clinical papers, semistructured interviews with various health professionals (gynecologists, obstetricians, etc.), and media analysis focused on videos of health professionals posted in social media (YouTube, Instagram, etc.). The triangulation of the different empirical materials was managed through CAQDAS, working with coding towards the identification of thematic dimensions.

Results

The socio-anthropological literature has highlighted how the highly gendered construction of the disease can contribute to the diagnostic delay. Indeed, several authors pointed out how delegitimization and minimization of symptoms are more often suffered by people socially perceived as women, due to the androcentric and paternalistic conceptions that still permeate the health care system (Seear 2014; Jones 2015).

Our analysis shows how medical discourses embody cultural scripts on femininity and female sexuality. Illness narratives provided by patients are often framed within an understanding of female embodied experience naturalizing pain as a biological component of female physiology and of women's sexual socialization. Evidences of medical gaslighting and epistemic violence can also be traced in medical discourses.

Conclusion

Our analysis confirms the importance of social sciences contribution in the reflections about invisible chronic diseases, helping a full understanding of the sociocultural factors impinging upon diagnostic delay and poor patient compliance. Particularly for conditions and illnesses that have a strong gender connotation, it is fundamental to critically reflect on the impact that health practitioners' conceptions about the disease and the ideal-typical patient have on practitioner-patient interaction, diagnosis, and therapeutic alliance. In addition, the intersectional approach highlights how different patient characteristics (e.g., sex, gender identity, class, race, educational level) and their intertwining affect the interaction with health professionals by hesitating in different levels of epistemic violence.

Dance, music and workout: an analysis of men's digital illness narratives on TikTok

Valeria Quaglia (University of Macerata)

Introduction

Social media in general, and TikTok in particular, carry interesting implications for both the emergence of new opportunities for accessing and sharing illness narratives and the self-representation of masculinities. TikTok is a popular social media platform and provides a new site for analyzing digital health narratives. Although TikTok offers some features that were already available on previous platforms such as YouTube, Instagram or Facebook, it also introduces specific functionalities that enable the creation of new types of content compared to the past. TikTok allows users to produce, share, and access short videos that last a maximum of 60 seconds. The specificities of TikTok have interesting implications for the emergence of new ways of sharing one's experience of illness, as well as for the self-representation of masculinities. In recent decades, the possibility of sharing and accessing illness narratives has increased exponentially with the advent of social media (Lamerichs et al., 2021), and this has had a significant impact on how people understand, signify, and experience their illness. In the field of digital media research, a new genre has emerged: digital health narratives (e.g. Svalastog et al., 2021; Lamerichs et al., 2021). These narratives are typically presented in the first person and are intended to be viewed, read or listened to by an audience; they are often publicly available and the platform on which they are shared usually allows readers to interact with the authors (Svalastog et al., 2021). This research focuses on TikTok, where users share their experiences with illness through short videos that can be easily found by searching for related hashtags. The relationship between health, illness, and gender is explored on the platform. Drawing from Connell's relational theory and its further developments, gender is considered an ongoing process of 'doing' - a configuration of practices that changes depending on the phase of life of women and men and historical and social contexts. Talking about or 'doing' health is part of these configurations of practices that occur in specific social and cultural contexts. The research focuses on problematizing the construction of men's self-representations of illness on TikTok, particularly in relation to men and masculinity.

Methodology

The data for this study was sourced from the TikTok platform. To create the corpus of data, an initial search was conducted using the keywords 'diabete tipo 1' (type one diabetes). The search results included the most popular videos, determined by the number of views and likes per video. The first 100 videos were then screened. The next step involved identifying the hashtags most relevant to the topic under analysis, namely, type 1 diabetes. The chosen hashtags were ordered based on their relevance to the topic and their potential to identify Italian-produced content. To select the sample of content creators, specific inclusion and exclusion criteria have been applied, resulting in a final sample of 7 TikTokers. This research analyzes 100 TikTok videos to investigate whether the visual self-presentations of diabetic men are influenced by stereotypical portrayals of hegemonic masculinity

or if there has been a shift in traditional constructions of gender identity due to the necessity of managing the disease and the emergence of new affordances provided by the TikTok platform.

Results

The analysis reveals three primary areas where elements of hegemonic masculinity intersect with traditionally feminine traits, allowing for new and hybrid ways of performing masculinities in relation to health and illness. These areas, which will be discussed in the presentation, include the display of the diabetic body, presentation of dietary habits, and displays of men's emotional states. Overall, TikTokers do not perceive illness as an unfortunate fate that renders them passive victims. Instead, they adopt an active approach and negotiate the meaning associated with health-related practices, showing traits like being autonomous, rational, and in control. This suggests compliance with treatment and a hybridization of masculinity ideals.

Conclusions

The self-representations of diabetic men on social media platforms can provide insight into the ongoing shifts in masculinities. This insight reveals how practices related to health intersect with gender practices, giving rise to new ways of enacting diabetic masculinities. Understanding how men negotiate health-related practices in the context of chronic illness is crucial to provide better care assistance to this part of the population and promote gender equality in health.

The Straw that Broke the Camel's Back: Experiences of Social Burden among Breast Cancer Survivors in Gaza

Walaa Ammar-Shehada (Ghent University), Piet Bracke (Ghent University), Melissa Ceuterick (Ghent University)

Background

Breast cancer is the most prevalent cancer among women in Palestine, accounting for one-fifth of all cancer cases. The link between breast cancer and unfavorable experiences post-illness is well-documented. However, there has been limited focus on the role of contextual factors outside the healthcare system in shaping the experiences of patients in Gaza. Recently published literature on the perceived support and social challenges in the lives of breast cancer survivors through a cross-sectional survey revealed that approximately 80% of these women felt supported after their illness, either fully or partially, primarily by family members, non-governmental organizations, spouses, and peers. Despite this, nearly half of the survivors reported experiencing negative social changes following their illness, and around 40% of the women who were married or previously married perceived negative changes in their marital relationships. The experiences of survivors were found to vary based on factors such as age, marital status, motherhood, type of treatment received, the absence of informal social support, and the lack of spousal support among married or previously married women.

Objective

This qualitative study explores how social-cultural factors can either amplify or attenuate prospects for social support following a breast cancer diagnosis. The aim is to analyze narratives of individuals diagnosed with breast cancer to examine how the illness influences social support and hence their post-illness experiences.

Methods

The data was collected through non-participant observation and interviews between September 2020 and April 2021. Forty semi-structured interviews, including thirty-eight with breast cancer survivors, were analyzed using a grounded theory approach.

Results

The results revealed three prominent categories significantly influencing patients' experiences. The initial challenge involves the public societal stigma surrounding a cancer diagnosis, where individuals either pity the patient or constantly emphasize the imminent threat of death. These stigmatized cancer-related discourses and

practices affect women's social interactions and roles. The second is specific to (ex)married participants. It reveals how the foundation of marriage prior to the illness is a determining and influencing factor in the experience of women after illness. The stigma associated with breast cancer significantly impacts marital dynamics, testing the wife's role, mainly in less robust marriages. The third category demonstrates how individuals with specific social identities such as mothers, and women engaged in a peer support group combat illness and challenge mainstream stigma through self-categorization or engagement in specific institutional setups that provide a better base of social support. The first two categories restrict social support for patients, resulting in a more negative experience, whereas the third category provides adequate support, shaping a positive post-illness experience.

Conclusions

The study presents three main socially constructed categories that either contributed to positive or negative 'lived realities' through the narrative of breast cancer survivors. It acknowledges that each individual's experience remains distinctly unique, however, the study concludes that breast cancer acts as a figurative magnifying glass, illuminating latent social practices in the community. This highlights the need to strengthen existing social bonds by addressing the fragility of ties within distinct social categories among survivors.

Implications

The research indicates the importance of implementing tailored support interventions that align with the unique needs of each group of survivors. Additionally, raising awareness within patients' social networks about the illness and how to provide support, coupled with enhancing survivors' financial security, may contribute to more effective coping with the social consequences of the illness.

Migration and Ethnicity in Health, Regular session – Chair: Yolanda Gonzalez – Room K.202

Clinical interventions during labor and childbirth among refugees and asylum seekers: A scoping review

Alix Bukkfalvi-Cadotte (Swansea University Medical School), Gargi Naha (Swansea University Medical School), Helen Snooks (Swansea University Medical School), Amy Brown (Swansea University School of Health and Social Care), Ashra Khanom (Swansea University Medical School)

Introduction

Refugee and asylum seeking women are generally less likely to access adequate antenatal care and some evidence suggests poorer perinatal outcomes among this population. Indeed, some literature reviews report higher perinatal mortality, miscarriages, stillbirths and perinatal mental health disorders among refugees.

However, there is a lack of high-quality quantitative data on perinatal clinical interventions among people seeking sanctuary and the findings reported in the literature show inconsistent trends in regard to some interventions, such as caesarean sections. The goal of this scoping review is to document the evidence regarding the rates of intrapartum clinical interventions among refugees and asylum seekers in high-income countries as compared to other population groups.

Methodology

We conducted a scoping review of peer-reviewed studies published in English since 2011 that report original quantitative findings regarding intrapartum clinical interventions among refugee and/or asylum seekers in high-income countries as compared to those in any non-refugee or non-asylum-seeking population group.

We searched four academic databases using search terms related to the refugee population, maternity care, and outcomes of interest. All the references were uploaded into Endnote and duplicates were removed. We then

exported the citations into an Excel spreadsheet to track the screening process. Titles and abstracts were screened for against the inclusion criteria. We retrieved all potentially relevant sources in full and assessed them in detail against the inclusion criteria. This process was independently conducted by two reviewers.

We extracted the data using a data extraction tool adapted from the JBI methodology guidance for scoping reviews template. The data extracted included the following:

- Author(s)
- Year of publication
- Study setting
- Study group and comparison group
- Key findings that relate to the scoping review aim.

Where unadjusted odds ratios (ORs) were not presented in the publications, we calculated an OR using the available data to facilitate comparison across the studies. We then compared the results reported in the included papers regarding five types of intrapartum interventions: induction or augmentation of labor, utilization of pain relief, caesarean sections, instrumental deliveries, and episiotomies.

Results

A total of 24 publications were included in the review. The findings indicate lower odds of clinical pain relief utilization among refugees and asylum seekers, with ten out of 14 unadjusted ORs ranging from 0.22 (CI: 0.15-0.32) to 0.96 (CI: 0.70-1.32). Similarly, findings indicate lower odds of instrumental delivery among refugees and asylum seekers: 11 unadjusted ORs range from 0.25 (CI: 0.15-0.39) to 0.78 (CI: 0.47-1.30), two ORs indicate no difference between groups with a null value of 1.00, and three ORs, none of which are statistically significant, are greater than 1.00.

We found no discernable trend in the data concerning the rates of labor induction and episiotomies. While caesarean section rates were the most commonly reported interventions in the included publications, the findings reported in the literature tend to diverge.

Conclusion

The studies included in this review suggest that asylum seekers and refugees are less likely to receive clinical pain relief and instrumental delivery than other population groups in high-income countries. These findings are consistent with the literature showing racial and ethnic disparities in pain management, which could be linked to differences in individual preferences and expectations, communication barriers between patients and care providers, differences in physiological response to pain, and inequities or discrimination in clinician decision making. The use of epidural analgesia in labor is, in turn, associated with higher rates of obstetric interventions, including instrumental vaginal deliveries, which is consistent with the data showing lower rates of clinical pain relief and instrumental delivery among refugees and asylum seekers.

Additional research into subgroups of people seeking sanctuary, potential confounders, and varied institutional and national settings is needed to further our understanding of the links between immigration status and maternity care, ultimately informing policy and practice to improve perinatal health and the provision of care for all.

The stigmatization of patients with a migration background suffering from depression in Belgian general practices

Camille Wets (Ghent University)

Depression is a prominent mental health concern in Belgium, affecting nearly one in ten Belgians (9.4%). It is particularly important to address depression among people with a migration background within the Belgian population. Studies across Europe have found higher prevalence rates of mental health problems such as depression and similar findings have been observed in Belgium. Notwithstanding the evidence suggesting a higher prevalence of depression among people with a migration background, recent studies indicate that these patients face additional challenges in accessing adequate medical care and are underrepresented in mental health services. Research has demonstrated that people with a migration background may face obstacles when seeking mental health care, including structural, cultural and linguistic barriers.

However, recent studies have shed light on the possible impact of health care providers on disparities in mental health care utilization. In this way, researchers have come to assume that general practitioners (further referred to as GPs) may contribute to ethnic disparities in mental health care use by inadvertently relying on stereotypes when evaluating and referring depressed patients with a migration background. This can lead to divergent treatment and referral outcomes when compared to native patients. While research on this possible provider bias among European GPs is limited, findings by Ceuterick and colleagues (2020) and Delaruelle and colleagues (2022) suggest evidence of a provider bias among Belgian GPs. These results underscore the crucial role that Belgian GPs can play in reducing ethnic disparities in mental health care use. Given their central role as gatekeepers in the Belgian primary health care system, GPs have the power to apply (unconscious) stereotypes when assessing and referring patients with a migration background. Ultimately, this can lead to (unintentional) stigmatization of these patients and GPs can (unintentionally) contribute to disparities in mental health care due to the stigmatization of patients with a migration background.

Consequently, this study aims to examine the stigmatization of patients with a migration background suffering from depression in the accounts of Belgian GPs. Nineteen in-depth interviews and four focus groups with Dutch-speaking GPs were conducted. Employing Link and Phelan's (2001) theoretical framework of stigma, a critical discourse analysis will be performed in order to explore the potential stigmatization of these patients. Our study emphasizes the significance of Link and Phelan's (2001) conceptualization of stigma, highlighting the essential role of power to the social production of stigma. Given the expert and gatekeeping role of GPs, we anticipate that this aspect will play a central role in our findings. Additionally, the four interrelated components of stigma ('labelling differences', 'stereotyping differences', 'separating "us" from "them"' and 'status loss and discrimination') will guide both the discourse analysis of the in-depth interviews and focus groups and the interpretation of our final findings. In this way, we believe this study can contribute to the field of research on stigmatization and ethnic disparities in mental health care in an innovative way. The ultimate goal is to formulate constructive recommendations based on the obtained results to support general practice, in order to prevent unconscious stereotyping and stigmatization of patients with a migration background suffering from depression. Consequently, we aim to remove barriers to access to high-quality mental health care for these patients in the Belgian health care setting.

Mental health stigma among ethnic minority and majority adolescents: The role of causal attributions

Lies Saelens (Ghent University), Piet Bracke (Ghent University), Fanny D'hondt (Ghent University), Melissa Ceuterick (Ghent University)

Introduction

Mental health difficulties and the associated stigma constitute a global public health concern. In various European countries, including Belgium, approximately one-fifth of adolescents experience moderate to severe

mental health issues (Kirtley et al., 2019; Sacco et al., 2022). Despite this high prevalence, open discussions about mental health remain taboo, contributing to a hesitancy among adolescents to seek both informal and professional treatment (Clement et al., 2015). Public stigma emerges as the most important barrier to help-seeking among young people (Gulliver et al., 2010). Causal attributions, representing beliefs about the aetiology of mental health difficulties, are recognized as pivotal in shaping stigmatizing attitudes and influencing help-seeking behaviors (Corrigan et al., 2003). Consequently, they are often targeted in education-based anti-stigma interventions. However, existing literature has predominantly focused on adults, leaving a gap in research exploring this association among adolescents. Furthermore, while scholars indicated the existence of cultural variations in stigma (Abdullah & Brown, 2011; Rao et al., 2007), this remains a largely unexplored area, especially outside the United States. Little is known about the perceptions and beliefs regarding mental health difficulties among non-Western populations and ethnic minority groups in Western European societies. Hence, the current study aims twofold: firstly, to investigate the association between causal attributions and stigma among adolescents; secondly, to explore potential cross-cultural variations in causal attributions and stigma and examine their relationships among both ethnic majority and minority adolescents.

Methods

This study employs a quantitative dataset from a cross-sectional study named the Red Noses Culturally Sensitive Stigma Survey (RN-CSS). Our research group developed and implemented a culturally sensitive stigma survey tailored to adolescents (ages 16-18 years) of different ethnic/cultural backgrounds, based on the Stigma in a Global Context Mental Health Study (Pescosolido et al., 2013). A total of 5035 adolescents from 38 secondary schools in Flanders completed the questionnaire. Respondents were presented with a vignette depicting a peer with symptoms of depression. Causal attributions, encompassing psychosocial, biogenetic, personal/moral, supernatural, and lifestyle attributions, and individuals' desire for social distance were assessed through questions referring to the vignette person. Multilevel regression models were used to investigate the effect of causal attributions on the desire for social distance, with separate analyses for ethnic majority and minority adolescents.

Results

Our preliminary findings reveal intriguing differences in stigma patterns between ethnic minority and majority adolescents. Notably, ethnic minority adolescents demonstrated significantly less social distance from peers experiencing mental health difficulties compared to their majority counterparts. Moreover, variations in causal attributions were observed between the two groups, with biogenetic and psychosocial attributions more frequently held by ethnic majority students, and spiritual attributions more frequent among ethnic minority students. Concerning the relationship with stigma, the results indicate that psychosocial attributions are significantly associated with lower levels of social distance, while personal/moral attributions are linked to higher levels of social distance.

Conclusion

Our findings add to the underexplored literature on mental health stigma among majority and minority adolescents. Implications for future anti-stigma campaigns include support for targeting causal attributions and developing differential interventions across cultural groups.

Using pension payments to understand return migration and subsequent mortality among Finnish migrants in Sweden

Olof Östergren (Stockholm University; Karolinska Institutet), Agneta Cederström (Stockholm University), Kaarina Korhonen (University of Helsinki), Pekka Martikainen (University of Helsinki; Max Planck Centre for Demographic Research)

Introduction

A considerable literature has been devoted to understanding differences in mortality between migrants and

natives. Accurately estimating mortality rates among international migrants remains difficult since this group by definition moves between contexts. Some scholars have suggested that migrant mortality rates may be underestimated if migrants in poor health return to their country of origin to receive medical care or to be with their family. This explanation relies on several assumptions on migration behavior and health that are difficult to assess in national register data. We exploit information on pension payments paid abroad to examine international migration patterns and mortality rates after return migration, or migration to a different country, among Finnish migrants in Sweden.

Methodology

The population comprises all persons born in Finland and Sweden between 1938 and 1955, alive in 2003, and living in Sweden at the age of 64, the legal age of retirement, and followed for mortality until 2021. We obtain information on monthly pension payments from the national pension agency which allows us to track the country of residence and vital status after an individual has emigrated from Sweden. We link information of pension payments to other registers containing demographic characteristics, socioeconomic position and use of health care services before return migration. First, we estimate the potential bias in mortality rates introduced by censoring at return migration and second, we use sequence analysis to identify post-retirement migration patterns in the Finnish-born group.

Results

Censoring at return migration did not bias estimates of mortality differentials between natives and migrants. Following adjustment for education and income, migrants who left Sweden had in fact lower mortality than migrants who remained ($RR=0.93$), suggesting that return migrants had on average better health than those who remained.

We found four distinct clusters of migration behavior: (1) remaining in Sweden, (2) flexible migration between Finland, Sweden and a third country, (3) immediate return migration to Finland and (4) eventual return migration to Finland. Migrants remaining in Sweden throughout the observation period was by far the largest cluster. Male sex, having no family in Sweden and good health predicted post-retirement return migration. Relative to migrants who remained in Sweden, those who migrated between Finland, Sweden and a third country had higher mortality ($RR=1.28$). In contrast, mortality rates were lower among the immediate ($RR=0.47$) and eventual returnees ($RR=0.45$).

Conclusions

Mortality differences between Finnish migrants and native Swedes were not biased by selective return migration. This was largely due to the substantial proportion of migrants who continued to reside in Sweden, coupled with the modest differences in mortality rates between those who remained and those who returned. We found distinct mortality patterns according to post-retirement migration behavior among Finnish migrants in Sweden. Migrants returning to Finland had on average lower mortality, while those who migrated frequently between several countries had higher mortality.

It is not clear if the observed patterns can be generalized to other contexts. Nevertheless, our results demonstrate that pension payments paid abroad is a promising tool for studying demographic processes and health among international migrants, especially if combined with other administrative data.

The impact of racism across the life course on mental health during the COVID-19 pandemic

Patricia Irizar (University of Manchester), Dharmi Kapadia (University of Manchester), Harry Taylor (King's College London), Laia Bécares (King's College London), James Nazroo (University of Manchester)

Introduction

The impact of racism on the mental health of ethnic minority people is well-evidenced. However, existing

research is limited, as most studies focus on racism experienced at any point in a person's lifetime or within a short time frame, impeding our understanding of the chronicity and accumulation of experiences of racism. Racism operates at structural and institutional levels, generating and reinforcing disadvantage across interconnected societal systems, resulting in inequitable opportunities in employment, housing, education, and healthcare. These inequities were exposed and exacerbated by the COVID-19 pandemic, as ethnic minority people were disproportionately impacted in terms of health (e.g., greater risk of infection and mortality) and economic outcomes (e.g., greater risk of income/job loss). This analysis aims to explore the direct associations between experiences of racism across the life course and self-reported common mental disorders (CMD) during the pandemic, and the indirect associations, through the disproportionate health and economic impacts of COVID-19, increased loneliness, and decreased feelings of belonging. We theorize a dose-response relationship, whereby the strength of the association increases with cumulative exposure to racism. The timing of exposure is also considered important, with recent experiences theorized to have stronger associations than past experiences of racism.

Methodology

This analysis used cross-sectional data (Feb-Nov 2021) from the Evidence for Equality National Survey (EVENS), the largest survey of ethnic minority people in Britain, obtaining responses across 21 ethnic groups. The survey measured experiences of racism across 10 domains (e.g., insulted, property damaged, treated unfairly in employment) and across four time periods (in the past year, past five years, past 10 years, over 10 years ago). Participants could endorse each domain and each time period, meaning cumulative exposure to racism could be calculated (ordinal variable reflecting increasing number of domains and time periods). An additional 4-level categorical exposure variable was created, capturing (i) no experiences, (ii) past experiences only, (iii) recent experiences only, (iv) both past and recent experiences of racism. The outcome was self-reported CMD, i.e., depression (≥ 4 , CES-D-8) and/or anxiety (≥ 10 , GAD-7) during the COVID-19 pandemic. The potential pathway variables included previous COVID-19 infection, change in household income, financial concerns, loneliness, and sense of belonging. Exploratory regressions, adjusting for covariates (age, sex, educational attainment, marital status, country of birth, month of survey completion), were conducted to assess the associations between (i) experiences of racism and CMD; (ii) experiences of racism and potential pathway variables; (iii) potential pathway variables and CMD. Generalized Structural Equation Modelling (GSEM) will be used to explore the direct and indirect effects of racism on CMD, through the potential pathway variables. The analyses were restricted to people from ethnic minority groups (excluding White British), aged 18-60 (N = 8,897).

Results

The preliminary results suggest a dose-response relationship between experiences of racism across the life course and the odds of reporting CMD during the COVID-19 pandemic, with effect sizes increasing with the number of domains and time-periods that were endorsed. Those who experienced racism across all domains and time periods were 4.7 times more likely to report CMD compared to those who had not experienced racism (95% Confidence Intervals [CI]: 3.6 to 6.1). Recent experiences of racism were associated with twice the odds of reporting CMD (95% CI: 1.6 to 2.5), whereas past experiences were associated with 1.5 times the odds (95% CI: 1.2 to 1.9), and chronic experiences (both past and recent) increased the likelihood of reporting CMD 3-fold (95% CI: 2.4 to 3.7). Recent and chronic experiences of racism (but not past experiences) were associated with reduced income during the pandemic, concerns about financial security, and a reduced sense of belonging during the pandemic. All levels of exposure to racism were associated with greater feelings of loneliness. Similarly, reduced income, concerns about financial security, greater feelings of loneliness, and a reduced sense of belonging, were strongly associated with greater odds of reporting CMD. Racism was not associated with previous COVID-19 infection and previous infection was not associated with CMD.

Conclusion

Despite the cross-sectional nature of the data limiting the ability to understand causality, the measures in EVENS capture experiences across the life course which can be used to assume temporality. Cumulative exposure to racism has incremental negative effects on the mental health of ethnic minority people. Racism, particularly recent and chronic experiences, contributes to adverse experiences during the COVID-19 pandemic (e.g.,

financial insecurity, loneliness) that may subsequently result in poor mental health. This work demonstrates the importance of capturing how experiences of racism accumulate over the life course, with detrimental consequences.

Intersectionality and Syndemics: Theoretical and Methodological Challenges, Thematic session – Chair: Philippe Bos – Room K.203

Multimethod Investigation into Ghanaian and Nigerian Youth's Experiences of Care for Depression and Anxiety in London

Anthony Isiwele (University College London)

Background

Adolescents today face numerous social, economic, and environmental challenges, with mental health being a critical area of concern. This study zeroes in on Ghanaian and Nigerian adolescents residing in Inner London, examining their experiences with mental healthcare, particularly in dealing with depression and anxiety. It also explores the influence of cultural, family, and educational factors on their mental health.

Methods

The research employed Interpretative Phenomenological Analysis (IPA) and Intersectionality-Based Policy Analysis (IBPA) methodology. It involved observing services and conducting semi-structured interviews with 27 participants. These included 12 youths aged 16-25 of Ghanaian and Nigerian descent, 10 parents, and 5 practitioners from the NHS's Improving Access to Psychological Therapies (IAPT) program and other community settings.

Results

This section offers a detailed account of the findings, delving into the themes that emerged from the interviews. It describes how cultural identity, stigma, and societal pressures shape the mental health experiences of these youths. The section highlights the participants' struggles with balancing their cultural heritage with the challenges of adapting to life in London. Specific attention is given to the role of familial dynamics, experiences of racism and bullying, and the challenges in accessing mental health services. The use of direct quotes from participants adds depth to the discussion, illustrating the intersectionality of their experiences.

Conclusion

The conclusion synthesizes the findings, emphasizing the need for culturally sensitive mental health services and policies. It discusses the implications of the study for mental health practitioners, policymakers, and the broader Nigerian and Ghanaian communities in London. The research underscores the importance of intersectional approaches in understanding and addressing the mental health needs of immigrant youth. It also identifies limitations of the study and suggests directions for future research, such as exploring comparative experiences in different urban settings or among different immigrant communities.

Implications

This study highlights the crucial need for culturally sensitive and inclusive mental healthcare, advocating for approaches that acknowledge and respect the unique backgrounds of adolescents. Its findings underscore the importance of culturally informed policies and interventions that foster mental well-being and resilience in diverse adolescent populations.

Syndemic vulnerability in Dutch urban cities: Investigating Health Disparities and Intersectionality

Evelien Dubbeldeman (Leiden University), Matty Crone (Maastricht University), Hedwig Vos (Leiden University), Rimke Vos (Leiden University), Nienke Slagboom (Leiden University), Dennis Mook-Kanamori (Leiden University)

Background

Health and social issues often cluster and interact in neighborhoods facing challenges like income, housing, and employment, leading to a much lower quality of life, referred to as "syndemics." However, current research into syndemics tends to overlook population diversity, including factors such as sex and ethnicity.

Sex disparities in clustering of health problems have been identified, with women experiencing a combination of psychological and somatic conditions, while men predominantly face combination of somatic conditions (Project SHIFT). Syndemic vulnerability also varies between sex, as demonstrated by a Dutch study highlighting clusters of musculoskeletal pain, cardiovascular diseases, and psychological problems. These conditions are associated with psychosocial factors, socio-demographic factors, and health behaviors, with higher prevalence among women. One methodological issue is the uniform application of syndemic approaches, neglecting population diversity in sex, ethnicity, sociodemographic differences, and their interaction. Syndemic research emphasizes the importance of including an intersectionality lens when examining the clustering and interaction of health conditions. Previous research in gay and bisexual men revealed disparities influenced by individual factors (sexual identity, age, SES) and broader contextual influences. Ferlatte identified specific risks, including identifying as gay, being single, young, lacking a university degree, and having a lower income, while Quinn emphasized the impact of stigma, oppression, and structural inequities, particularly affecting young gay and bisexual men and intensifying vulnerability for black individuals. An intersectionality-informed syndemic approach, considering sex, age, and ethnicity, could offer more insights into the mechanisms and systems creating clustering and interaction in syndemic suffering, providing a deeper understanding and identifying groups most affected by structural inequalities.

We aimed to identify sex-specific clusters and interactions of health and adverse social conditions as potential contributors to syndemic vulnerability and health inequalities, and examining the influence of intersectionality on these patterns.

Method

Our study focused on adult residents in Leiden and The Hague, two urban cities in the Netherlands, registered at different general practices linked to the Extramural LUMC Academic Network (ELAN) database. We used existing routine health data from the ELAN database linked with Central Bureau for Statistics information, encompassing sociodemographic characteristics.

We included adults who were registered with a general practitioner in 2018 and 2019, had a minimum of two registered health conditions documented by their general practitioner, lived in Leiden or The Hague, and were at least 18 years old in 2018.

Descriptive statistics identified prevalent health condition clusters in sex and age groups. Regression analyzes assessed how common health problem clusters interacted with healthcare use and costs on additive and multiplicative scales. We examined prevalence and interaction differences between men and women, considering the frequency and impact of clusters across sexes and age groups.

Results

A total of 43,340 adults were included for analyzes, revealing differences in health condition combinations for men and women. In men aged 18-34, the most common combination was mood/anxiety disorders and autism/AHDH (n=447, 11.8%), while women predominantly experienced mood/anxiety disorders with abdominal complaints (n=925, 15.2%). Women aged 35-49 showed a similar pattern (n=807, 15.1%), with additional combinations of neck/back problems with abdominal complaints (n=710, 13.2%) and mood/anxiety disorders (n=670, 12.5%). The prevalent combination in men was neck and back problems with mood/anxiety disorders

(n=360, 9.6%). Women aged 50-64 faced combinations of hypertension with abdominal complaints (n=690, 11.3%), neck/back complaints (n=653, 10.7%), and mood/anxiety disorders (n=651, 10.6%). Men commonly experienced hypertension with diabetes (n=541, 11.0%) and cardiovascular diseases (n=533, 10.8%). In both men and women aged 65 and above, hypertension with musculoskeletal disorders was the prevailing combination (n=1436, 26.0% and n=2008, 25.8%, respectively). Another prevalent combination in women was hypertension and cardiovascular diseases (n=1855, 23.8%).

Conclusion

Our study highlighted distinct health condition clusters within sex and age groups. Women experience a broader range of health issues, often characterized by mental and psychosomatic symptoms like mood/anxiety disorders and abdominal complaints. Conversely, men exhibited a higher prevalence of specific physical conditions, including hypertension, diabetes, and cardiovascular diseases. The findings align with previous research, suggesting the importance of further exploration into the role of intersectionality in syndemics.

Currently, we are investigating the foundations of these disparities, including interaction analyses and Multilevel Analysis of Individual Heterogeneity and Discriminatory Accuracy (MAIHDA). Using MAIHDA, we will examine the interplay and heterogeneity of intersectionality and syndemic vulnerability, quantifying intersecting factors (ethnicity, SES) and assessing their impact at individual and group levels.

Building on this, future research could further explore syndemic vulnerability by examining the impact of gender-related characteristics, offering a more comprehensive understanding of how distinct health condition clusters differ between men and women. Pelletier indicated that factors like gender roles, relations, identity, and institutionalized gender may correlate with an increased burden of risk factors for cardiovascular diseases, irrespective of biological sex. Exploring gender-related features in syndemic vulnerability could offer valuable insights into health disparities, guiding targeted interventions for diverse populations.

Culturally safe healthcare for homeless Indigenous peoples in Montréal: An intersectionality-informed Two-Eyed Seeing research project

Jessica Neicun (University of Montréal), Stéphanie Marsan (University of Montréal), Julie Bruneau (University of Montréal)

Introduction

While Indigenous peoples (Inuit, First Nations and Métis) are over-represented among marginalized populations in Canada (1), those living in urban areas are more exposed to deprivation and homelessness (2, 3). By October 2022, 13% of homeless people in Montréal were estimated to be Indigenous, while they only represent 0.6% of Montréal's population (4). Indigenous homelessness encompasses individuals, families and communities (5); it is generally concomitant with the lack of stable and appropriate housing or by continuous circular displacement between Indigenous communities and urban areas (6-8). Beyond homelessness, Indigenous peoples have developed biological and psychological responses to intergenerational trauma caused by colonialism, which includes emotional deregulation, chronic and infectious diseases, spiritual unsolved grief, and mental health issues (9-11). Adaptive responses to intergenerational trauma can thus be seen as the embodiment of devastating lived experiences involving interpersonal relationships, as well as relationships between persons and physical and social environments (12). Embodiment is further shaped by the socio-structural conditions of deprivation, marginalization and geographical segregation wherein Indigenous peoples evolve, which results in a diversity of disease dynamics. From the perspective of syndemic theory, the way in which biological components of disease synergistically interact with social and environmental factors promotes and/or reinforces the negative effects the latter may have on individuals' health (13). However, these synergistic interactions occur under socio-political dynamics of power and privilege that influence health disparities, which are not sufficiently accounted for by syndemic theory (14-16).

A comprehensive understanding of health needs of homelessness Indigenous peoples in Montréal must therefore encompass the intertwined individual, social and contextual determinants of Indigenous health (17-19). In order to be culturally relevant, such an endeavor requires the adoption of a way of thinking that goes beyond the empirical axiom of a unified physical universe to include spirituality and nature in the quest for knowledges (20, 21). Yet colonialism has been accompanied by an epistemic domination that relegates Indigenous knowledges and ways of knowing - based on observation, experiential learning, spirituality and connection with the natural world - to a second place in favor of a positivist empiricism - specific to the Western scientific paradigm - that privileges neutrality and objectivity (20-24). To overcome this epistemic asymmetry, this research adopts an "*Etuaptmumk*/Two-Eyed Seeing" approach, which in Mi'kmaq means "learning to see, with one eye, with the strength of Indigenous knowledge and, with the other eye, with the strength of Western knowledge" (25-27). This guiding principle combines ontology, epistemology, methodology, and axiology from Western (biomedicine, epidemiology, and social sciences) and Indigenous knowledge systems (21, 28, 29).

The conceptual framework is completed by an intersectional approach intended to account for power dynamics operating among healthcare professionals and Indigenous peoples (16). Intersectionality has as main goal to decipher how knowledge of Indigenous realities along with perceptions about cultural safety and (institutional and interpersonal) racism within the hospital (30-32) vary according to healthcare professionals' intersecting identity categories (ethnicity, sex/gender, age, socioeconomic status). Intersectionality is also intended to help better understand dynamics of privilege and exclusion that underlie interactions between hospital staff and Indigenous patients (24, 33-41).

The overall aim of this study is to improve the healthcare provision for homelessness Indigenous peoples at the University of Montréal Health Centre (CHUM), while identifying the specific barriers experienced by healthcare professionals in delivering culturally safe healthcare.

Methodology

The study adopted a non-experimental design and mixed-methods approach that encompasses descriptive/bivariate analysis of survey data and thematic analysis of qualitative data collected through focus groups and individual interviews. A convenience sample was made up of healthcare professionals (MD, nurses and support staff) from CHUM's Emergency room, Internal Medicine Unit, Addiction Psychiatry and Addiction Medicine Units (n=200).

Results

Holistic understanding of Indigenous peoples' health problems due to intergenerational trauma is essential for the provision of culturally safe healthcare, which includes responses to patients' basic needs (e.g., food and clothes), building of trusting relationships through personalized care (i.e. extended consultation times, allowing the presence of patients' relatives), and regular collaboration with community workers. Healthcare professionals' reflexivity about their social position and acknowledgement of power imbalance between Indigenous and non-Indigenous Canadians facilitates the adoption of holistic approaches to care combining Western biomedicine and Indigenous spirituality and healing practices (e.g. smudging, beadwork). By contrast, lack of knowledge, misconceptions and racialized stereotypes about Indigenous peoples' worldviews and health behaviors appear as systemic barriers for cultural safety at CHUM. Finally, time constraints and absence of specialized resources such as interpreters and cultural mediators within the hospital appear to be the main organizational barriers for cultural safety.

Conclusion

This communication will focus on epistemic, theoretical and methodological challenges associated with intersectional research using a Two-Eyed Seeing approach. It will develop on knowledges, misconceptions, and racialized stereotypes mobilized by healthcare professionals in their interactions with homeless Indigenous peoples, underlying their implications in terms of delivery of culturally safe healthcare.

Exploring syndemic vulnerability among adolescents living in urban cities in the Netherlands

Samantha Groenestein (Leiden University), Evelien Dubbeldeman (Leiden University), Sabine Plag (Leiden University), Matty Crone (Maastricht University), Robert Vermeiren (Leiden University), Suzan van der Pas (Leiden University), Jet Bussemaker (Leiden University)

Background

The increase of multimorbidity (the co-occurrence of two or more health conditions) in adolescents in welfare states is a major concern for current and future population health and requires a different care approach. The syndemic theory may contribute to gaining more insight on the way health conditions cluster, are driven by social contextual factors and exacerbating adverse health outcomes in individuals and populations. Syndemic research in an adolescent population is still limited and currently lacking research in high-income countries such as the Netherlands. Mapping adolescent syndemic vulnerability will provide a better understanding of the mechanisms that potentially contribute to the social and health inequalities among individuals living in average urban Dutch cities, such as The Hague and Leiden.

We aim to explore which clusters of health conditions are prevalent among adolescents, aged 10- to 19-years-old who are registered at general practices in the Dutch urban cities of The Hague and Leiden. Also, which social and contextual factors contribute to these clusters of health conditions, and the extent in which the clusters are related to health care use and costs.

Methods

We used general practitioner's registration data of diagnoses from the Extramural LUMC Academic Network (ELAN) database to explore multimorbidity based on the two-year prevalence of 20 health conditions in an adolescent primary care population (n=10.841). Latent Class Analysis (LCA) was used to distinguish different multimorbidity classes. Information on social contextual factors operating at the individual (e.g. migration background), family (e.g. divorced parents and parental (physical/mental/somatic) health conditions) and household (e.g. SES) level was linked from routinely collected and registered administrative and societal data from Statistics Netherlands. Multinomial logistic regression analysis examined multimorbidity class differences in social contextual factors, health care use and costs.

Results

25.7% (n=2,781) Adolescents were registered as having at least two health conditions between 2018 and 2019. We identified four multimorbidity classes of disease clusters in the multimorbid adolescent group: 'Asthma-Skin conditions' (n=442), 'Skin conditions' (n= 794), 'Behavioral disorders and skin conditions' (n=565), 'Gastrointestinal and mental disorders and pain complaints' (n=980). Overall, each class differed significantly in associated individual and social factors. All classes, compared to adolescents without any current health conditions, were more likely of having parent(s) with a physical and/or somatic health condition, mental health disorder, and social problems. The majority of the classes also more often had social problems or were victim of a criminal act. All classes had more yearly contacts with the GP, and had higher healthcare costs and were more often in contact with youth care services than the no morbidity group. The adolescents in the 'Skin conditions' class however had more GP visits than the adolescents in the other classes. The adolescents within the 'Behavioral-skin conditions'-class were more often in touch with youth care services and the adolescents from the 'Gastrointestinal- and mental-pain condition' class had higher healthcare costs.

Conclusion

Our findings suggest that multimorbidity is prevalent in adolescents living in urban cities in the Netherlands, that multimorbidity classes of disease clusters are driven by social and contextual circumstances and that these classes show differences in health care use and costs. Our results support the need for integrated preventative measures focusing on both individual and societal aspects. Health care should focus on recognizing diverse

perspectives and needs of patients and stimulate interdisciplinary collaboration between healthcare and welfare.

Our study comes with some limitations, as we included a selection of health conditions, the adolescent population may not always visit the GP while having symptoms or visit another GP than their regular GP. Also, the ELAN database does not include all GPs in the Hague and Leiden. However, to the best of our knowledge, this is the first study to explore multimorbidity patterns in adolescents using GP-registered data combined with societal data of both adolescents and their parents. Another strength of our study is the use of a LCA, as using LCA to explore multimorbidity patterns may be superior in identifying multimorbidity clusters compared to other clustering techniques, because of its accuracy in identifying multimorbidity clusters.

For future studies it is important to gain more insight into syndemic vulnerability among adolescents and its persistence over the life course, in order to study if syndemics that start during adolescence persist over the remainder of life and lead to increased health and social inequalities later in life.

3 July: 13:30 – 15:00

Global Health, Regular session – Chair: Tania Dube – Room K.101

Medicalized Female Genital Cutting: Exploring Decision-Making Evolutions, Dynamics, and Cultural Variances among Maasai and Abagusii Ethnic Groups

Jolien Inghels (University of Antwerp; Research Foundation Flanders), Samuel Kimani (University of Nairobi), Nina Van Eekert (University of Antwerp; Research Foundation Flanders), Peter Stevens (Ghent University), Sarah Van de Velde (University of Antwerp)

Introduction

Female genital cutting (FGC) is a practice defined as the partial or total removal of the external female genitalia for non-medical reasons (WHO, 2023). In Kenya, where the current study is situated, the prevalence of FGC is slowly decreasing. Simultaneously, the practice is increasingly performed by medical health professionals rather than traditional circumcisers, indicating increasing medicalization rates (Kenya National Bureau of Statistics et al., 2014). Given the health consequences and the human rights violations surrounding the practice, performing FGC is prohibited by law in Kenya, regardless of who performs it (National Council for Law Reporting, 2011). These rising medicalization rates present new challenges in addressing the issue of FGC. The literature on FGC underscores the complexity of this practice, rooted in cultural, social, and gender norms. Earlier studies have focused on coordinating change in norms and behavior among people interacting with one another as a key strategy for promoting behavior change in the practice, starting by identifying key actors in the decision-making process concerning FGC (Matanda et al., 2018). However, how this information unfolds within the newly emerging evolutions in the practice has not yet been identified. To inform policymakers on how to understand this rising phenomenon of medicalized FGC, this research aims to unravel the poorly understood dynamics of medicalized FGC decision-making by examining why and how the shift towards medicalization influences the decision-making process concerning a girl's cut, identifying key actors, and exploring variations across different birth cohorts and ethnic groups.

Methods

The study employed a qualitative approach, conducting 60 face-to-face semi-structured in-depth interviews with mothers with at least one living daughter within the Maasai ethnic group in Narok County, and the Abagusii ethnic group in Kisii County, in Kenya. To obtain data saturation, different background characteristics were factored in such as age, education level, employment, etc. This focus allowed for a nuanced understanding of decision-making dynamics and variations within these ethnicities. Transcripts of these interviews were coded

and analyzed thematically, applying researcher triangulation. Links were made with various Kenyan grassroots organizations and activists working in the field to gain insight into how the findings should be interpreted.

Results

Preliminary results show several important findings contributing to a better understanding of FGC medicalization and its evolutions. We found crucial insights into the agency for Maasai young women concerning medical decision-making, signaling a shift in power dynamics. Furthermore, we found a normative framework surrounding medicalization among Abagusii mothers, indicating how medicalization could function as a new social norm. The study also identified how its evolutions, underlying reasons for medicalization, and key actors in the decision-making differ between these ethnic groups.

Conclusion

This study contributes valuable insights into the ongoing evolution of FGC practices, particularly the increasing medicalization in Kenya among two ethnic groups. The findings highlight the agency of Maasai young women in medical decision-making and the normative framework concerning medicalized FGC among Abagusii mothers. The observed variations in decision-making dynamics between the Maasai and Abagusii communities underscore the complexity of FGC practices, the unique cultural nuances, and influences shaping decisions within different ethnic groups, highlighting the multifaceted nature of the medicalization trend in Kenya. By unraveling these dynamics, the research provides a foundation for understanding and addressing the complexities surrounding FGC, offering potential avenues for targeted interventions and policy improvements.

Improving access to care for socio-economically vulnerable populations in Belgium: Lessons from Brazil and South Africa

Laura Vroonen (University of Antwerp), Caroline Masquillier (University of Antwerp), Hilde Bastiaens (University of Antwerp), Linda Campbell (University of Antwerp), Katinka De Wet (University of the Free State), Katarinne Lima Moraes (University of Brasilia), Edwin Wouters (University of Antwerp)

Introduction

Access to Primary Healthcare (PHC) is key to progressing towards Universal Health Coverage and is an essential component of Sustainable Development Goal (SDG) 3: Ensuring good health and wellbeing for all at all ages. In recent years however, inequality in access to PHC has increased in Belgium. People who live in socio-economically vulnerable circumstances in particular struggle to get the care they need due to a myriad of intersecting and mutually reinforcing individual and organizational barriers. Action is needed to break the vicious circle of poor health contributing to poverty and social exclusion clustered in disadvantaged communities, further exacerbating health disparities.

A promising path to address these continuous challenges is to learn from successful existing interventions. In this regard, Brazil was identified as a potential example, having been designated a top performer on progress towards universal access to care. Brazil offers a proactive PHC model with a strong focus on outreach by community health workers (CHWs). CHWs are lay members of the communities where they live and work, who receive training to provide comprehensive health support for all household members, thereby bridging the gap between PHC and disadvantaged communities. Inspired by the success of the Brazilian model, South Africa has started to “re-engineer” its own primary healthcare system. This includes a shifting role for CHWs away from vertical, disease-specific interventions towards the provision of preventive cradle-to-grave health support as an integrated part of multidisciplinary teams, known as ward-based primary healthcare outreach teams (WBPHCOT).

Valuable lessons can be learned from both countries - in different stages of implementing this community-based PHC model - to inspire the development of outreach interventions for disadvantaged communities in Belgium. This qualitative study therefore aims to identify the PHC model's underlying mechanisms and contextual factors in order to inform the development of a similar outreach model in Belgium.

Methods

Qualitative fieldwork in South Africa (September – October 2023) consisted of 39 semi-structured interviews with various key stakeholders and 11 days' observational field notes. Stakeholders were purposively selected based on their expertise and experience, with the help of local contacts, and included academic experts, policy makers, members of the health teams and community members. Data collection for the Brazilian model consisted of an extensive literature review and a field visit to primary care clinics in Rio de Janeiro and Brasilia as well as meetings with health policy makers (November 2023). Data analysis was performed in accordance to the thematic analysis procedures described by Braun and Clarke. Specific attention was paid to the different phases of implementation and how they can inform expanding access to care in Belgium.

Results

The findings contribute to a deeper understanding of the program theory underlying the PHC models in Brazil and South Africa. Several factors influencing program effectiveness were identified. First, macro-level contextual factors include the availability of clear policy guidelines, the level of political support and the resources dedicated to implementation. Due to considerable regional autonomy in both countries, program implementation was found to therefore vary strongly between provinces and clinics. Secondly, at the level of the health facilities, CHWs function best when their role is recognized by other health professionals and they are regarded as an integrated part of the multidisciplinary health teams. Being at an earlier stage of implementation, this provides a particular challenge in South Africa as it faces challenges in shifting from a disease-specific focus to a comprehensive, integrated PHC model. Third, community actors are of importance as they offer both social and technical support for CHWs, for example by providing a working space or a vehicle. Finally, CHWs' performance relates to individual factors such as knowledge, skills, stated job satisfaction, etc. Insufficient training and precarious working conditions in South Africa often lead to frustration and decreased motivation amongst CHWs, despite strong statements of personal commitment to improving their community's health.

Conclusion

The articulation of an intervention's functional mechanisms and its contextual dependency is a necessary first step in the transfer and adaptation across settings. Inspired by the lessons from Brazil and South Africa, this study will inform the development of an outreach-oriented PHC model with community health workers in Belgium, in order to improve access to PHC for people living in vulnerable socio-economic circumstances and who are not (adequately) reached today.

'What matters most' and health-related stigma: Results from a qualitative study in Indonesia and Nigeria

Ruth Peters (Athena Institute; Free University Amsterdam), Marlies Visser (Athena Institute; Free University Amsterdam), Olien Sopamena (Universitas Indonesia), Sutiawan (Universitas Indonesia), Dadun (Universitas Indonesia), Uchenna Innoeze (University of Nigeria), Emeka Nwefoh (University of Nigeria), Lawrence Yang (New York University)

Introduction

Individuals with stigmatized conditions not only have to deal with their health condition, but also face adverse attitudes from others and social exclusion, stemming from preconceived notions about the condition and its associated symptoms or links to disability. Recent research on health-related stigma recognizes that stigma is a complex social phenomenon, but also elucidate the similarities between manifestations and consequences of stigma across conditions and the opportunities this brings. A key gap is the lack of understanding on how the influence of culture can be taken on board in more 'generic approaches' to assess and reduce stigma. Yang et al. consider stigma as moral experience; everyday engagements defining 'what matters most' and 'personhood' in a local context. This suggests that stigmatizing experiences may be impacted by local cultural dynamics. This study aims to capture culture-specific stigma dynamics related to leprosy, lymphatic filariases (LF) and depressive disorder by understanding 'what matter most' in Indonesia and Nigeria.

Methodology

In this qualitative study we conducted a total of 50 interviews and 14 FGDs in Cirebon District, Indonesia, and 42 interviews and 14 FGDs in Enugu State, Nigeria. Comprising 91 and 112 respondents, respectively. The Indonesian and Nigerian field team consisted of researcher from the local study area. The study population included i) people diagnosed with leprosy, depressive disorder or LF, ii) the family members of people with any of these three conditions, and iii) healthcare workers. We used purposive and quota sampling techniques. To capture how culture relates to stigma, we adapted the “What Matters Most” framework which has been applied in studies on a variety of stigma-related conditions. The topic guide consisted of an introduction, what matters most related questions (e.g., about being a good/proper person and achieving ‘what matters most’), lived experiences relating to stigma focusing on marriage and personal relationships, accessing, and maintaining work and/or education, domestic tasks, the family name/honor and community participation. Data was audio recorded and transcribed verbatim. Qualitative analysis was completed through thematic content analysis.

Results

We identified key thematic areas to matter most across contexts including; individual character and integrity, marriage, children and family responsibilities, community responsibilities and religion. In Cirebon, key engagements included being a provider and authority in the family (for men), caring for the family and managing the household (for women), being well-mannered and engaging in ‘gotong royong’, referring to mutual cooperation, in the community. In Nigeria, key engagements included; clean and neat appearance, social responsibility and integrity, role as provider (for men), ability to conceive (men and women) and bear healthy children (for women). Key engagements under these themes provided potential to worsen stigma and/or resist stigma. For example, if a person does not show or is not able to show mutual respect, they will lose their personhood in the eyes of the community and in turn, may no longer receive reciprocal respect or assistance.

Conclusion

By discerning the experiences of people with stigmatized conditions, family members and health care providers, we gained a more comprehensive understanding of the factors contributing to stigmatization against individuals with specific health conditions. Engaging with ‘what matters most’ in stigma research enables increased sensitivity to cultural dynamics in stigma measurement and highlights markers for interventions. A limitation of this study is that it was conducted in one subculture in Indonesia and Nigeria, which limits the generalizability.

Investigating socioeconomic & demographic determinants of adverse child health outcomes in the Indian subcontinent: A cross-national assessment of the weathering hypothesis

Sharlene Alauddin (University of Exeter; Khulna University), Sarah Walker (University of Exeter), William Henley (University of Exeter)

Introduction

Young and advanced maternal age, ethnic diversity, and socioeconomic background are associated with adverse birth and child health outcomes and play significant roles as contributing factors in health disparities. Evidence is accumulating that chronic exposure to such social and economic inequalities can lead to the acceleration of normal aging, termed the ‘maternal weathering hypothesis.’ Limited studies have explored its impact in low- and middle-income countries (LMICs). This study investigated the relevance of the maternal weathering hypothesis for understanding the impact of social inequalities on childbirth and health-related outcomes in the Indian subcontinent.

Methodology

We used data from Demographic and Health Surveys in India (2019-2021), Bangladesh (2017-2018), Pakistan (2017-2018) and Nepal (2016). Associations between maternal age and offspring-related outcomes (birthweight, stunting, wasting, underweight) were examined using linear and logistic regression. Birthweight was considered as the primary outcome. The functional form of the effect of maternal age was modelled separately using

polynomial terms and through categorization of age (<20 years, 20-24 years, 25-29 years, 30-34 years and >34 years). The impact of ethnicity and socioeconomic factors on maternal weathering was assessed by introducing interaction terms into the regression models. Ethnicity was categorized on a country-specific basis, reflecting self-reported ethnic affiliation, language, and caste or tribal group (in India). The cumulative household living standard (wealth index) was measured using principal components analysis by considering household asset ownership. The wealth index was grouped for the interaction analysis into two categories. The magnitude of relative inequalities in health outcomes, expressed as ratios among ethnic / socioeconomic groups, was estimated using Theil's index.

Results

In the baseline analysis, we analyzed data on 1,61589 live births to mothers in India. There was a U-shaped pattern in the overall effect of maternal age on birthweight and other offspring-related outcomes, with lower mean birthweights identified for younger mothers and mothers aged over 35. This decrease in birthweight of newborns for older mothers was more apparent in those belonging to the lower ethnic group (defined based on self-reported tribal groups: scheduled tribe and other backward class (OBC)), both before and after adjustment for potential confounders (mean decrease relative to higher ethnic group of 43 grams, 95% CI: -79.37 to -6.80, p-value = 0.019). Further analysis explored the impact of alternative measures of social and economic disadvantage in explaining accelerated decline in infant health outcomes in India. For wealth, we found a marginally significant decrease of 25 grams (95% CI: -2.23 to 52.49, p-value = 0.0718) in birthweight among mothers aged ≥ 35 years belonging to the 'poor' socioeconomic class compared to mothers of the same age in the wealthier socioeconomic class. Notably, mothers with below a secondary education and aged over 35 years, had a mean 52-gram decrease in birthweight (95% CI: 22.97-81.12, p-value < 0.001) compared to mothers with at least a secondary education. This effect remained after adjustment for other confounders (59.80, 95% CI: 21.47 to 98.12, p-value= 0.002). Further work will be presented extending the testing of the weathering hypothesis for birth and infant health outcomes in Bangladesh, Pakistan and Nepal, and making cross-national comparisons.

Conclusion

Children of advanced-aged mothers who belong to a socioeconomically-deprived and lower social caste in India are disadvantaged at birth and in maintaining nutritional status, providing evidence to support the relevance of the weathering hypothesis for explaining infant health inequalities in LMICs. The findings of this study aim to contribute to attaining the sustainable development goal of 'Good health and well-being' by advocating effective policies to eradicate unjust social inequalities and improve health outcomes in the LMICs of the Indian subcontinent.

Health Behaviors and Lifestyle, Regular session – Chair: Tim Huijts – Room K.102

Understanding dietary practices of men and women from six countries in light of evidence-based information

Anna Prokop-Dorner (Jagiellonian University), Małgorzata Maraj, Sylwia Wrzecha, Michalina Gajdzica, Karolina Majdak, Marija Franka Žuljević, Danielle Maria de Souza Serio dos Santos, Luciane Cruz Lopes, Laís Lessa Neiva Pantuzza, Lehana Thabane, Long Ge, Qi Wang, Tina Poklepović-Peričić, Pablo Alonso-Coello, Bradley Johnston, Gordon Guyatt, Małgorzata M. Bała

Introduction

Beliefs and practices defining our daily dietary choices are closely linked to our lifestyle and habits shaped by the cultural context. The existing body of research suggests they are rather stable and difficult to change. The aim of our study was to explore people's dietary beliefs and practices linked to consumption of products high in fats and the level of willingness to change them when faced with evidence on cardiovascular health effects. Our analysis specifically investigated gender differences in regard to changing dietary preferences.

Methodology

We conducted a mixed-methods study consisting of three phases: exploratory interviews, a survey (CAWI) and semi-structured interviews with members of academic communities in Brazil, Canada, China, Croatia, Poland and Spain. In Phase One we explored dietary preferences linked to products high in fats and then formulated questions regarding beliefs and practices for the questionnaire basing on the findings. In Phase Two we presented respondents with evidence-based health information on cardiovascular health effects of a dietary change and measured their level of willingness to introduce suggested dietary alternation (measured on a scale from 1 to 7). We also asked about their beliefs and preferences linked to consumption of products high in fats. Based on this data we developed an inventory consisting of 3 subscales, the results of which ranged from 0-100. To better understand the observed quantitative trends, we are currently conducting Phase Three on a purposeful sample of the respondents from Phase Two.

Results

We collected data from 3633 respondents from six countries (65.9% women). We found a significant difference in the mean level of willingness to introduce a change between women and men, with women reporting a higher level ($p < 0.001$). Furthermore, we analyzed correlations between willingness to change and the statements regarding practices and beliefs linked to buying, preparing and eating products high in fats. Preliminary results from the selected countries suggest that significantly more women agreed with the beliefs positively correlating with willingness to change and more men declared those beliefs which correlate negatively with willingness ($p < 0.001$). Additionally, women significantly more often presented behaviors conducive to healthy choices, such as controlling products high in “unhealthy” fats and using products high in “healthy” fats. Men, on the other hand, significantly more often declared dietary choices dictated by taste and convenience ($p < 0.001$). Finally, women scored significantly higher on all subscales measuring beliefs and practices linked to fat elimination, awareness of fat content and avoidance of trans fats ($p < 0.001$).

Conclusion

Our preliminary results show a greater willingness to introduce dietary changes when faced with evidence-based health information among women than men. The reasons for those trends might be connected with gender norms which in our study translated to the beliefs and behaviors conducive to (not) avoiding fats, (not) following dietary cravings and (not) conforming to current dietary recommendation. The qualitative data from Phase Three should equip us with in-depth understanding of strategies of searching and verifying health information in women and men, which could be crucial in the studied context.

The operationalization of intersectional research in physical activity, sedentary behavior, and sleep: A scoping review of research methods

Gaia Segantin (UMC Amsterdam; Amsterdam Public Health) Usman Sani Dankoly (Glasgow Caledonian University), Linda Schoonmade (Free University Amsterdam), Fawad Taj (UMC Amsterdam; Amsterdam Public Health), Mai ChinAPaw (UMC Amsterdam; Amsterdam Public Health)

Introduction

Intersectionality is a theoretical framework, first brought up by Law Professor and Gender Studies Scholar Kimberlè Crenshaw in 1989, that implies to consider the multiplicative effect of belonging to different marginalized social groups on a human factor (i.e. a health status, health outcome, behavioral pattern, etc.). Recently, intersectionality has been more commonly applied to public health research to better understand health inequalities across certain subgroups. Understanding the social correlates of health allows to better target public health policies and interventions.

A major aspect of public health and prevention is physical activity and lifestyle. Human movement behaviors (physical activity, sedentary behavior and sleep) have recently been studied together, as inter-related aspects of 24/7 human movement behaviors. Intersectionality applied to physical activity data research has recently

been operationalized, with fewer cases of application to the fields of sedentary behavior and sleep. Intersectionality theory has been operationalized employing different methodologies (quantitative, qualitative and mixed-methods). No guidelines exist on how to take into account intersectionality theories when analyzing 24/7 human movement data, and so far multiple models, methods and approaches have been employed in order to depict the multiplicative effect of belonging to various stigmatized social groups simultaneously.

The aim of the study is to systematically order, describe and categorize the methodologies employed for operationalization of intersectionality analyzes on physical activity, sedentary behavior, and sleep.

Methodology

A scoping review is being conducted to systematically categorize the methodologies for operationalization of intersectionality analyzes in the fields of physical activity, sedentary behavior and sleep. The scoping review protocol will be registered on OSF.io. The review employs the PRISMA (extension for scoping reviews) protocol for inclusion and exclusion of studies. The search string combines with Boolean operators twosub-strings focused on intersectionality, and movement behaviors. Pubmed, Embase and Scopus databases will be searched. Rayyan and Endnote are used as supporting software for managing the review flow of activities and the references.

A data extraction template has been designed to gain information from each study and answer to the following research questions:

1. What are the methodologies employed for operationalization of intersectionality analyzes in 24/7 human movement behaviors research?
2. Which intersections of social identities are analyzed??
3. What are the rationales behind each methodology (qualitative, quantitative and mixed-methods) employed for operationalization of intersectionality analyzes of 24/7 human movement behaviors?

Results

The impact of this research will be to classify the available studies on the topic of intersectionality applied to 24/7 human movement behaviors in order to list and extensively describe the available methodologies for operationalization of intersectionality analyzes, defining the purposes and rationales of each methodology. Ultimately, the present scoping review can serve as guidance to conduct intersectionality analyzes in 24/7 human movement behaviors research.

Cross-country differences in sleep quality in later life: The link between health behaviors and sleep

Katharina Loter (Tilburg University), Claudia Recksiedler (German Youth Institute)

Introduction

Ample studies demonstrated a strong link between the quality of night sleep and individuals' mental health (e.g., Alcántara et al., 2016; Baglioni et al., 2016; Freeman et al., 2020). According to a more recent cross-sectional study involving individuals aged 16-74 years from 20 European countries (Baranowski & Jabkowski, 2023), the primary determinants of sleep quality are health-related issues and depression, and the role of individual characteristics is more important than national ones. However, this study also revealed age-specific differences, with individuals aged 45 years and older being more likely to experience restless sleep than their younger counterparts. In the second half of life, several life course transitions, including retirement, bereavement, or illness, have the potential to disturb sleep patterns and affect both well-being and mental health. Approximately 50% of older adults reported to have experienced challenges with initiating or maintaining sleep (e.g., Crowley,

2011). Such sleep difficulties are associated with an elevated risk of substantial morbidity and mortality. Because the consequences are more severe for older compared to younger adults, especially concerning an increased risk of death and disability (Rodda et al., 2011), our study specifically targets individuals aged 50 years and older. Adding to the longitudinal evidence on this matter, our objectives are twofold. First, we aim to unveil sleep dynamics in a cross-national comparison, and second, to identify and group health behaviors—both protective and destructive—that are associated with sleep quality over time.

Methodology

We use data from the Survey of Health, Aging and Retirement in Europe (SHARE), which is a cross-national panel study that samples Europeans aged 50 years and older (8 waves; 2004-2019). Our outcome variables are the average duration of night sleep and sleep problems at each wave. The focal predictors of interest are prospectively tracked health behaviors, such as physical activity, diet, weight loss or gain, and drug consumption (i.e., regular use of tobacco and/or alcohol). Based on previous findings associating lower SES, physical and/or mental disorders, and grief with sleep problems (Arber et al., 2009; Baranowski & Jabkowski, 2023; Lancel et al., 2020), we also take into account socio-economic-related inequalities and the occurrence of critical life events and illness in our analyzes. We explore sleep dynamics using hybrid models for panel data (e.g., Bell et al., 2018; Schunck, 2013). We utilize hybrid models that encompass both random-effects and fixed-effects estimates, permitting the consideration of separate within-cluster and between-cluster effects (Bell et al., 2018). Separate hybrid models are fitted for each country to assess the similarity among the individual country estimates (see e.g., Uccheddu et al., 2019 for a similar analytical approach).

Results

Preliminary analyzes revealed significant cross-country variations in sleep quality and (un)healthy lifestyles across Europe. While some older adults maintain a steady sleep routine over the years, others report changing sleep patterns (e.g., getting less sleep and having worse sleep quality), often triggered by illness, retirement, or bereavement. Regular physical activity emerged as a pivotal protective factor for sleep, while drug consumption was identified as a destructive one. An improvement in health behaviors was associated with enhanced sleep quality and quantity.

Conclusion

Our findings underscore the importance of aiding (older) adults in adapting their health behaviors to ensure adequate sleep and increase their quality of life in the second half of life. We interpret and discuss our findings through the lens of the biopsychosocial model, which considers the interplay of biological, psychological, and social factors.

Health literacy and lifestyle behaviors in older adults: Exploring the moderating role of social connectedness

Maud Wiecek (Swiss Centre of Expertise in Life Course Research LIVES; University of Lausanne), Clément Meier (University of Lausanne), Matthias Kliegel (Swiss Centre of Expertise in Life Course Research LIVES; University of Geneva), Jürgen Maurer (Swiss Centre of Expertise in Life Course Research LIVES; University of Lausanne)

Background

Lifestyle behaviors such as hazardous alcohol use, smoking, and poor diet significantly impact global health and mortality. Integrating nutrition and lifestyle changes is crucial for improving older adults' health span and quality of life. Health literacy, referring to the knowledge, motivation, and competencies necessary to access, understand, appraise, and apply health information to make judgments and take decisions in everyday life concerning healthcare, disease prevention, and health promotion, may play a key role in this context. However, the relationship between health literacy and lifestyle behaviors, especially among older adults, remains under-explored. Also, considering that individuals tend to draw on the health literacy of members of their social network

and the importance of the social environment for older adults' overall health and well-being, social factors have been suggested as targets to help buffer the adverse effects of insufficient health literacy. Therefore, the present study aimed to i) investigate the relationship between health literacy levels and the number of unhealthy lifestyle behaviors in a population-based sample of older adults living in Switzerland and ii) explore the potential moderating role of both quantitative and qualitative aspects of social connectedness in this relationship.

Methodology

We used data from 1,455 respondents to Wave 8 (2019/2020) of the Survey of Health, Ageing, and Retirement in Europe (SHARE) in Switzerland.

Four unhealthy lifestyle behaviors were considered to derive the number of unhealthy behaviors: current smoking, risky alcohol consumption, suboptimal daily consumption of fruits/vegetables, and lack of engagement in vigorous physical activity.

Subjective health literacy was measured with the short version of the European Health Literacy Survey questionnaire (HLS-EU-Q16). Three categories were derived from the total score: inadequate health literacy levels (0-8), problematic health literacy levels (9-12), and sufficient health literacy levels (13-16).

Social connectedness was assessed using the Social Connectedness Scale. The scale includes five main characteristics of the social network into a composite measure to capture the key facets of social network resources in a single indicator: size, geographical proximity, contact frequency, very or extremely close emotional ties and diversity. Social isolation was defined as a score equal to or greater than 3.

Associations were examined using Poisson regression models, controlling for sociodemographic and health characteristics and including an interaction term between health literacy and social connectedness to test the moderation hypothesis.

Results

Overall, 72.2% of respondents reported at least one unhealthy behavior. The respective prevalence of problematic and inadequate health literacy levels was 22.6% and 8.0%. One-fifth of the sample (20.6%) was considered to be socially isolated.

When controlling for key sociodemographic and health-related variables, higher health literacy scores were significantly associated with having a lower number of unhealthy lifestyle behaviors (Average Partial Effect [APE]=−0.02, $p<0.01$). Also, respondents with inadequate health literacy levels were significantly more likely to have a higher number of unhealthy lifestyle behaviors than respondents with sufficient health literacy levels (APE=0.21, $p<0.05$), holding other characteristics fixed. We found a significant interaction between health literacy and social connectedness ($p=0.04$), with a stronger positive association between inadequate health literacy and the number of unhealthy behaviors in socially isolated individuals (APE=0.34, $p<0.05$).

Conclusions

Greater social connectedness seems to buffer the positive association of low health literacy with unhealthy lifestyle behaviors in older adults. Given the potential spillover effects that health literacy may have on others through its potential transmission in social networks, enhancing health literacy could empower older adults to effectively seek and apply health information, thereby improving lifestyle management. The study also suggests that public health interventions should include community or family elements to boost social connections and address isolation. Tailoring these interventions to varying levels of health literacy could help alleviate the combined burden of low health literacy and unhealthy behaviors in older age.

Gender and Health, Regular Session – Chair: Piet Bracke – Room K.103

The disclosing stories project: Qualitative study with working class women on sexual violence and health

Karen Lorimer (Glasgow Caledonian University), Pamela Ritchie (Glasgow Caledonian University), Lesley McMillan (Glasgow Caledonian University)

Globally, progress on gender equality is slowing or even stalling, such that the 2022 SDG Gender Index ‘sounds the alarm on gender equality’ (EM2030 2022). Tackling gender inequality, and specifically gender-based violence, requires an intersectional approach, which the 2022 SDG Gender Index calls for. Such an approach is embedded within Scotland's Women's Health Plan, published August 2021. But while gender is obviously central to our understanding of sexual violence, we should not focus solely on gender, as this can obscure the lived reality of women from low-income backgrounds. This study sought to develop a rich picture of the ‘healthcare journey’ of working-class women, to better understand the nexus between gender, class and sexual violence, and develop a sense of needs, supports and barriers. The Disclosing Stories project engaged 19 working class women who had experienced sexual violence in qualitative episodic interviews. Women who identify as working class are not a homogenous group with similar experiences and needs. Women who located class as economic AND psycho-social saw class in everyday life, offered episodic knowledge of being a working-class woman with a body that holds no value, as an object to castigate and with a voice to be dismissed. We consider the connections of this project to existing work on class and gender, and discuss the implication of these findings for healthcare responses to working class women. How do we dismantle the ‘brick-encased world’ one woman described she lived in?

Exploring the longitudinal relationship between work-family conflict and physical activity through a gendered lens

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Introduction

The increase in women's labor market participation has led to an increase in dual-earner couples, resulting in more individuals experiencing conflict between work and family roles, known as Work-Family Conflict. Studies show that stressors, such as Work-Family Conflict, are associated with both health-risk and health-promoting behaviors. This study focuses on the latter, namely the impact of Work-Family Conflict on physical activity, which has stress-reducing effects, improves mental and physical health, and ultimately reduces mortality. However, instead of benefiting from the stress-reducing effects, increasing Work-Family Conflict may also lead to time pressures that reduce the time available for physical activity.

As in many other areas, gender differences exist in physical activity and leisure time more generally: Studies show that leisure time, including physical activity, is unequally distributed between men and women, with men and fathers having more (child-free) leisure time. Considering gender when studying the impact of Work-Family Conflict on physical activity therefore seems crucial.

While the few existing studies suggest a negative association between Work-Family Conflict and physical activity, the specifics, especially regarding gender differences and the direction of conflict, remain inconclusive. Furthermore, all studies used cross-sectional data, often with small and/or specific samples, and only one study examined gender differences. This study aims to address these limitations by examining the longitudinal effects of Work-to-Family Conflict (WTFC) and Family-to-Work Conflict (FTWC) on physical activity by gender in an Australian sample of parents.

Theory

This study uses *Conservation of Resources Theory* to propose a mechanism of the relationship between Work-Family Conflict and physical activity. According to the theory, the loss or threat of loss of resources, such as time, leads to stress. Individuals have different strategies for coping with this stress: Shifting the focus of attention or reevaluating resources. In this case, due to a lack of time for work or family and therefore, increasing stress, an individual might reevaluate the resource of time and reduce the frequency of physical activity as work and family take priority.

Due to prevailing gender roles and based on a rational model of Work-Family Conflict, the area in which most women spend more time in is the family and for men it is work, which is also evident in the Gender Care Gap. Therefore, I assume that it is primarily WTFC that reduces men's physical activity and FTWC that reduces women's physical activity.

Methodology

Using data from the Household, Income, and Labor Dynamics in Australia (HILDA) survey and 18 waves, this study focuses on employed parents with at least one minor child. Physical activity is measured by frequency of at least 30 minutes of moderate or vigorous activity. Work-Family Conflict is measured by two items for each direction, which reflect the same by simply switching the source of conflict. Control variables include respondent's age, age of youngest child, number of children, equivalized household income. In total, I use information on 6,445 respondents and 45,410 observations. Ordered logit regressions with fixed effects are employed to examine the relationship of WTFC and FTWC on physical activity by gender, and accounting for within-individual heterogeneity.

Results

The descriptive results of the pooled sample confirm the gender gap in leisure time, with men having a higher frequency of physical activity. Spearman's Rho analysis indicates negative correlations between both WTFC and FTWC and physical activity, suggesting that increased conflict is associated with decreased physical activity. The results of the multivariate models show that high conflict in both directions is significantly associated with reduced physical activity, with WTFC having a greater effect on physical activity. However, moderate FTWC has no significant effect, but moderate WTFC does. When analyzing the results by gender, high FTWC loses significance for women, but remains significant for men. Notably, women experience greater decrease in physical activity due to WTFC compared to men's FTWC and WTFC.

Conclusion

This study highlights the importance of considering both the direction of Work-Family Conflict and gender when examining its impact on physical activity. WTFC emerges as the primary factor affecting physical activity, particularly for women, who still do most of the unpaid care work and whose stress may even increase without time for leisure. In contrast, high FTWC significantly reduces men's physical activity, but to a lesser extent. The findings suggest that women may be less able to benefit from the stress-reducing effects of physical activity as leisure time decreases due to WTFC. However, in times of family conflict, women may be better able to cope with stress, whereas men may not be as good at coping with increasing family conflict and therefore reduce physical activity to compensate for their lost time at work. These findings emphasize the need for further research on gendered leisure time dynamics in the context of Work-Family Conflict, recognizing potential differences in how men and women manage their leisure time during stressful periods.

Exploring changes in psychosocial functioning of trans people on gender affirming hormone therapy: A biopsychosocial approach

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Introduction

Gender Affirming Hormone Therapy (GAHT) is the most common and often only form of medical intervention sought by transgender (trans) people. There is abundant research supporting the positive impact of GAHT for trans people (1), including evidence for reduced symptoms of depression and anxiety (2) and some evidence for improved quality of life (1). Less well explored is the impact of GAHT on psychosocial functioning, an umbrella construct which reflects a variety of traits, characteristics and dispositions related to: well-being, self-mastery, and interpersonal functioning. Understanding psychosocial functioning during GAHT is of particular importance given that trans people report greater social disruption compared to cisgender people (3). Importantly, understanding of potential changes in psychosocial functioning is limited by the notable lack of qualitative inquiry amongst diverse samples of trans people with other intersecting identities (4). Such an approach is necessary to explore how GAHT may influence psychosocial functioning and the varying biopsychosocial mechanisms underpinning such influence. Additionally, there have been calls for research which gives voice to transgender people's lived experience of GAHT (5-7). This study sits within a larger ERC-funded project (Affirm Relationships) and aimed to explore the lived experience of trans people on GAHT from a biopsychosocial perspective.

Methodology

A qualitative methodology was, and is currently being employed to explore trans people's lived experiences related to how they perceive their psychosocial functioning since starting on GAHT. We are aiming to conduct 30 semi-structured interviews with trans people, representing those on different forms of GAHT (feminizing and masculinizing), with different gender identities (including non-binary), and various times since starting GAHT, as well as across age groups. We would also like this research to represent the voices of further marginalized trans people (e.g., racially minoritized people) where possible. Therefore, a triangulation of recruitment strategies are being employed through: The Amsterdam UMC gender clinic, relevant organizations (E.g. Transvsie and TransUnited) and word-of-mouth (supported by a group of key stakeholders). Interview schedules include questions to enable exploration of participant experiences of their well-being, feelings of self-mastery and interpersonal functioning along with how they perceive any changes to their relationships with others (including romantic partners, family, friends, etc.). Interview data will be analyzed using reflexive thematic analysis, combining both inductive and deductive approaches. Checks for methodological rigor include inter and intra coding techniques and member checking.

Results

Ten trans people (6 women, 1 man and 3 non-binary identifying) on GAHT have participated in an interview so far with 3 participants on masculinizing GAHT and 7 on feminizing GAHT). Preliminary results suggest that there are varying mechanisms by which GAHT may influence psychosocial functioning and trans people's relationship with others, with significant nuances between feminizing and masculinizing hormones, GAHT dose, and time since starting. Welcomed physical changes, hope for the future, and perceived acceptance by others were seen to be significant indicators of well-being, particularly in the early months of GAHT.

Feeling authentically oneself was a common reflection by participants after GAHT, and such authenticity enabled development of closer bonds with others. For participants on masculinizing GAHT, this happened through them feeling better able to prioritize relationships which served their authentic self. Participants on feminizing hormones often reflected on the contrast between previously feeling distanced and closed off from others to then allowing themselves to nurture deeper and more open connections after starting GAHT. They also described an increased ability to cry as a way to express their reactions. Another factor which influenced participants relationships with romantic others were changes in sex drive and sexual function.

Differences in mood and emotion regulation since GAHT were also voiced by participants. With masculinizing hormones, participants described low mood in the initial months. Participants spoke about becoming easily irritated, but feeling less overwhelmed by their emotions in the longer term, and being able to articulate and focus on the context of felt emotions. On the other hand, some participants on feminizing hormones described an enlarging of their emotions and fluctuations in mood. In some cases, this was seen to negatively impact psychological wellbeing when previous coping mechanisms could no longer be applied effectively.

Experiences of changes were often underscored by the social context in which participants lived. They reflected on how feelings of acceptance within society were instrumental in their feelings of self-esteem.

Conclusion

These results, along with insight gained from parallel participatory research, will inform the design of a prospective cohort study to isolate causal pathways between GAHT and psychosocial functioning. Such insight is paramount to ensuring health equity for trans people, particularly given that a number of study participants highlighted a need and desire for accessible and trustworthy information on the potential impacts of GAHT, and how to navigate social relationships during this time.

Unpaid work, childcare provision and health in Switzerland: a gender perspective

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Introduction

Unpaid work, encompassing domestic labor and childcare, may impact health and well-being, with distinct implications for men and women. This study investigates the effects of unpaid work on men and women's health in Switzerland, particularly examining whether variations in childcare provision across Swiss cantons influence these effects. Previous research highlights the physical and mental health stressors linked to unpaid work, often disproportionately borne by women. The unique Swiss context, characterized by varying childcare policies across cantons, provides an opportune setting to examine how policy interventions in childcare provision can affect health outcomes related to the burden of unpaid work.

Methodology

This quantitative study utilizes data from the Swiss Labor Force Survey, using multilevel regression analyses, controlling for socioeconomic and demographic variables, and a two-way fixed effect design. The analysis focuses on examining the association between unpaid work and self-reported health for both men and women, and whether variations in childcare provision across Swiss cantons and over time moderate this association using cross-level interactions. The differing approaches of the Swiss cantons to childcare provision, combined with changes in childcare provisions over time, offer a quasi-experimental setting to assess the impact of childcare policy. The outcome of this study is self-reported health, a robust indicator of general health status.

Results

Preliminary findings show that women engage more in unpaid work in Switzerland and report lower self-rated health compared to men. Multivariable analysis reveals significant gender disparities in health outcomes associated with unpaid work. Results from cross-level interactions show that increased childcare provision in Swiss cantons moderates the negative association between unpaid work and health for women, although this result is marginally significant. For men, however, this moderating effect is not as pronounced.

Conclusion

The initial results of this study indicate a clear gender differential in how unpaid work impacts individual health and the significant role childcare provision plays in moderating this impact. For women, enhanced childcare support in various Swiss cantons appears to mitigate the adverse health effects associated with unpaid work. This research contributes to the broader understanding of the health implications of unpaid work and the potential of targeted policy interventions, such as childcare provision, to address gender disparities in health outcomes. Indeed, these results suggest that policies enhancing childcare support can have a substantial effect on alleviating the health burden of unpaid work, particularly for women. Future research may explore the long-term health effects of unpaid work and childcare provision, and the replicability of these findings in other contexts.

Migration and Ethnicity in Health, Regular session – Chair: Theoni Stathopoulou – Room K.201

Income inequalities in mortality among migrants and their descendants. A Swedish population-based study

Andrea Dunlavy (Stockholm University), Alexander Miething (Stockholm university), Sol P. Juárez (Stockholm University)

Introduction

There is well-established evidence showing that international migrants experience a mortality advantage compared to native-born majority populations in high-income destination countries (1). In addition to this observation, migrants also often display weaker, inconsistent or non-existent income gradients in mortality relative to their native-born majority population counterparts. A recent study has further shown that income inequalities in mortality among migrants become more pronounced with increasing duration of residence, emphasizing the impact of the settlement context on health inequality development among migrants (2).

Yet the extent to which an income mortality gradient may also be evident among the descendants of migrants, one of the fastest growing and most diverse young adult population groups in Europe, has been largely unexamined. Existing evidence has revealed that the descendants of migrants experience health and mortality risk disadvantages relative to both migrants and their native-born majority population peers (3). However, limited efforts have been made to measure income inequalities in mortality across generations, i.e., among migrants and their children. Simultaneous assessment of income gradients in mortality among these groups can facilitate a deeper understanding of the long term social and economic integration processes of immigrants and their descendants, and how this relates to the formation and persistence of social and health inequalities across generations.

This study aims to assess the extent to which relative income inequalities in mortality are observed by nativity, age of arrival and generational status among persons with a foreign background in Sweden.

Methodology

The study employs longitudinal population registries that include the entire registered population in Sweden from 2004 to 2016. The study population includes foreign- and native-born individuals aged 25 to 64, and utilizes an open cohort design. Persons born in Sweden with two native-born parents were categorized as the native-born majority population. Persons with a migrant background were categorized into eight groups based on their own country/region of birth and age of migration or parental country/region of birth.

Using Poisson regression, we examine the associations between income rank position and mortality among men and women with migrant and non-migrant backgrounds. Income rank position is measured with information on individual disposable net incomes from the Longitudinal Integration Database for Health Insurance and Labor Market Studies (LISA) and involves the computation of the Relative Index of Inequality (4). Mortality is assessed with ICD-10 codes on recorded deaths from the Cause of Death register.

Results

Preliminary results suggest that, in line with previous findings (2), the magnitude of income inequalities in mortality among adult migrants are smaller relative to the native-born majority population, irrespective of region of origin. Relative inequalities were only marginally smaller in magnitude among European compared to non-European migrants.

Preliminary findings also indicated that income inequalities in mortality among descendants of migrants with European origin were largely similar to those observed among the native-born majority. Among non-European descendants, income inequalities in mortality exceeded those of the native-born majority among men, but not women, who approached convergence with native-born majority population women only in some groups. Additional preliminary analyzes showed that the higher relative income inequalities observed among men with non-European origin were primarily driven by mortality from external causes.

Conclusion

Income inequalities in mortality are weaker among migrants compared to the native-born majority population in Sweden and develop unevenly among the descendants of migrants, depending on gender and parental origin. Preliminary results suggest that income inequalities in mortality are most pronounced among men born in Sweden with non-European origin. Additional analyzes are planned to examine these associations further by investigating additional causes of death.

‘A role model is someone who...’ A multi-institutional study of clinical role models according to ethnic minority and majority medical students

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Introduction

Role modeling is an established teaching method in medical education, where medical students learn by observing more experienced physicians. Role models play an important role in students’ socialization, professional identity development, and career choice. In more recent years, role modelling has regained scholars’ interest in the context of the increasingly culturally diverse student body. However, it is a common conception that students who are ethnically underrepresented in medicine (URiM) do not have enough role models (Lempp, 2009, Spaans et.al, 2023).

In our pursuit to understand how ethnicity, in the form of student migration background and ethnic representativeness of role models, relates to how medical students view clinical role models, this study explores the ethnicity-related elements of the clinical role modelling process. The authors present the first empirical analysis of medical students’ clinical role model definitions. They use an innovative conceptual framework of a four-stage role modeling process (Idealization, Social comparison, Composition, and Behavioral and Symbolic Outcomes), in which they integrate theoretical advancements from sociology, humanities and economics. They aim to answer the research question: *How does students’ role model perception relate to student ethnicity and role model ethnic similarity?*

Methodology

Authors employed a convenience sampling technique (which later progressed into a snowball technique) where they emailed all eight Dutch medical schools and their student associations, asking them to invite their students to partake in the survey. This resulted in 363 students completing the statement ‘A role model is someone who...’. These answers were coded based on the conceptual framework. Students also indicated if and how many role models they have (Composition) and rated the ethnic similarity of their role model. URiM (N=62) and non-URiM students (N=301) were compared using χ^2 - and t-tests.

Results

Overall, more than half of both URiM students (32/62, 51.6%) and non-URiM students (167/301, 55.5%) had role models in medical school. Role models were most described as someone you want to be like (156/363, 43%), who is skilled (140/363, 38.6%), who you admire (87/363, 24%), and who inspires you (66/363, 18.2%). The least common attributes to describe a role model were their symbolic value (6/363, 1.7%) and how representative the role model is (7/363, 1.9%).

Although URiM and non-URiM students' responses were similar in number of role models and the reported role modeling stages, URiM students rated the ethnic similarity to their role models lower than non-URiM students. Students with less ethnically similar role models reported symbolic role model outcomes like inspiration and motivation less often. The figure below shows the conceptual framework of clinical role modelling, highlighting Symbolic outcomes as the only ethnicity-related stage of the role modelling process.

Conclusion

Comparing URiM and non-URiM students' role model definitions showed that URiM students do not look at role models inherently different than non-URiM students do. Rather, their perception of role models is related to how representative their role models are: URiM students rated the ethnic similarity to their role models lower than non-URiM students, and symbolic role model outcomes were reported less often by students with less ethnically similar role models. This suggests that a lack of ethnically representative role models interferes with equitable learning opportunities, because URiM students may not benefit from clinical role modelling the way non-URiM students do.

Reflecting on this study, authors conclude that students had difficulties reflecting on their role models and the process of social comparison because the role modelling process and in particular social comparison largely take place on a subconscious level. Especially URiM students may be reluctant to consider or report social comparison between them and their role model as this places emphasis on their minority background, which is exactly the stigma that they often work very hard to get away from.

Differences by ethnicity in the association between air pollution and ischaemic heart disease and stroke

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Introduction

Air pollution exposure is a major risk factor for cardiovascular diseases. In 2017, 21,900,000 DALYs and 977,000 deaths from ischaemic heart disease (IHD) and 3,950,000 DALYs and 184,000 deaths from ischaemic stroke (ISTR) were attributed to exposure to particulate matter alone.¹ Concurrently, the burden of cardiovascular disease is unevenly distributed across population groups, with generally higher cardiovascular disease risk among minority ethnic groups. In addition to the current knowledge on disparities in exposure to air pollution,^{2,3} knowledge on whether the effect of air pollution differs between ethnic groups can help to understand the role of air pollution in existing inequalities in cardiovascular disease. We aimed to explore differences in associations between air pollution exposure and incidence and mortality of ischaemic heart disease (IHD) and (ISTR) between the 6 largest ethnic groups in the Netherlands.

Methods

For this follow-up analysis between 2014-2019, we used nationwide individual-level data of residents of the Netherlands aged ≥ 30 years from the 6 largest ethnic groups. To be able to analyze first incidence of IHD or ISTR, we created two separate cohorts for analysis: one free of IHD and one free of ISTR. Information on IHD and ISTR diagnosis and mortality was obtained from hospital discharge and death registries and included ICD-10 codes I20-I24 for IHD and ICD-10 codes I63, G45 for ISTR. Sociodemographic data originated from the National Population Register and the tax register. All registers were centralized by Statistics Netherlands. Yearly average concentrations of nitrogen dioxide (NO₂) and particulate matter <2.5 micrometers (PM_{2.5}) were determined for the residential address in 2014. Ethnic group was defined based on country of birth. We performed Cox proportional hazards survival analyzes stratified by ethnicity with either IHD or ISTR as the dependent variable and either PM_{2.5} or NO₂ as independent variables. The analyzes are adjusted for age, sex, urbanicity and both

individual-level and neighborhood-level socioeconomic position (based on income and taxable assets). We included a random intercept for geographical regions to adjust for spatial clustering.

Results

The IHD cohort consisted of 9,528,581 people and the ISTR cohort consisted of 9,837,233 people. The mean (sd) air pollution concentrations in $\mu\text{g}/\text{m}^3$ at the residential address in 2014 were 13.3 (1.4) for $\text{PM}_{2.5}$ and 19.8 (5.0) for NO_2 . During the six-year follow-up period, 156,517 (1.6%) persons developed IHD and 127,673 (1.3%) persons developed ISTR. First regression results showed that the association between air pollution and ISTR differed notably between ethnic groups, with the highest hazard ratio for residents of Turkish ethnicity. Differences in hazard ratio's persisted after confounder adjustment. The analyzes are currently ongoing and all results, including the exact hazard ratios, will be available before the conference.

Conclusion

The first results suggest differences by ethnicity in the association between exposure to air pollution and cardiovascular diseases. This adds to the knowledge that air pollution lowering measures can reduce disease inequalities, especially if they focus on populations vulnerable to exposure.

Pathways to homelessness among Central and Eastern European labor migrants in The Netherlands

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Introduction

Homelessness among people with Central and Eastern European (CEE) migrant backgrounds is an issue of concern in several Western European countries, including the Netherlands, where migration from other EU countries is often motivated by perceived job opportunities. Our understanding of the emergence of homelessness among CEE migrants residing in Western European countries is limited. Therefore, the current research explored how CEE labor migrants become homeless in the Netherlands and if across their narratives, different pathways to homelessness can be found.

Methods

We conducted a qualitative study with semi-structured interviews with 42 Polish and Romanian labor migrants that experienced homelessness in the Netherlands. Employing the framework method and a combination of deductive and inductive coding, we analyzed the data to identify patterns of factors in the Netherlands and vulnerabilities before migration (including prior homelessness, mental health challenges and substance use struggles) in relation to the participants' becoming homeless.

Results

From our analysis, five pathways to homelessness emerged. Pathway 1, 'Loss of work as a singular event', covers most participants' accounts, in which job loss seemed to be the primary driver of becoming homeless. Particularly relevant for the majority of these participants was the combination of employment and housing in a single contract, which implies that employment termination directly results in loss of housing. Pathway 2, 'Prior vulnerabilities and multiproblem situations', represents individuals who, prior to coming to the Netherlands, already had several vulnerabilities, and who continued to have multiple problems throughout their stay in the Netherlands, including unemployment, substance use struggles and mental health challenges. For participants in pathway 3, 'Dissolution of a romantic relationship and loss of work', the ending of a romantic relationship appeared to be an important factor in their becoming homeless, in addition to reduced work hours or job loss. These participants' stories displayed a complex interaction between unemployment, a relationship ending, and, for some, substance use, that led to homelessness. Pathway 4, 'Homelessness upon arrival', includes participants

who were homeless directly upon arrival in the Netherlands. These participants also did not have a job prior to their homelessness. For participants in pathway 5, 'Serious health problem', their homelessness seemed to be closely tied to serious physical or mental health problems.

Conclusion

This study set out to better understand the emergence of homelessness of CEE labor migrants in the Netherlands and explore potential subgroups in this matter. We differentiated five pathways to homelessness, based on events and risk factors present during participants' stay in the Netherlands and prior vulnerabilities. An important strength of this study is the centrality of the voices of marginalized individuals and their perspectives on how they became homeless. Social workers interviewed our participants, and often had prior contact with them. Besides advantages, this could have had undesirable effects, for example on what social workers did and did not ask and on the formulations of questions. Also, clients are to some extent dependent on social workers for help and support. This power asymmetry could have influenced participants' answers. Policies aimed at preventing or reducing CEE labor migrant homelessness in the Netherlands and possibly other Western European countries should reflect the illustrated diversity in the ways these individuals become homeless. This implies taking and continuing measures focused at the specific vulnerabilities, factors and events present in the different pathways. For example, governments should explore encouraging or mandating all employers to separate employment and housing contracts. Also, access to mental health and addiction care for CEE labor migrants with substance use struggles should be improved. Such more targeted measures should be taken alongside more generic measures, such as taking early and preventive action, providing culturally sensitive support in people's own languages and providing shelter – the latter of which is currently not standard practice for homeless CEE labor migrants in the Netherlands.

Students in Transit: Resilience and psychosocial well-being among refugee adolescents in Greece

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Abstract

Research has documented the mental health challenges children and adolescents from refugee backgrounds experience due to several individual, family, community, and societal risk factors in their migration trajectory (Fazel et al., 2012; Scharpf et al., 2021). Despite exposure to adversity and stress to development, many children and adolescents from refugee backgrounds also show remarkable resilience and successfully adjust to their new lives (Dangmann et al., 2022). Access to education in emergency and post-emergency situations that provide opportunities for meaningful participation for children and adolescents from refugee backgrounds can restore a sense of safety and normality in their lives and enhance their resilience and social-emotional adjustment in the presence of substantial life challenges (Burde et al., 2016; Cerna, 2019). In the case of Greece, most families and children seeking refuge opt to resettle in countries of North and Central Europe where the living and working conditions are seen as more favorable. The migration trajectory of children and adolescents from refugee backgrounds in Greece, mainly a transit country for migration, can influence their educational and developmental outcomes, mental health, and social integration.

The paper will be based on data collected from the project "RaRE-Understanding Risk and Resilience in the Educational Performance of Refugee Children and Youth", conducted by the National Centre for Social Research (EKKE) in collaboration with the Harvard Program in Refugee Trauma (HPRT), Harvard University. The aim of the study is to address a significant lack of evidence-based research on the school attendance, educational outcomes, and psychosocial adaptation of refugee children enrolled in formal education in Greece. It investigates the risk and protective factors shaping the educational performance of school-aged accompanied and unaccompanied refugee children arrived in Greece, post the 2015 European refugee crisis. The study is nested at four interrelated

levels- individual, family, community, and society according to the integrative socioecological model (Suárez-Orozco et al., 2018).

The study population comprises a) refugee adolescents aged 12-18 years from countries with the highest number of school-age students enrolled in and attending the Greek educational system (namely, Syria, Iraq, Afghanistan, Somalia, and Ukraine), b) their parents or legal guardians in the case of the unaccompanied minors, and c) their teachers. We will present results from two psychometric tools: a) the Strengths and Difficulties Questionnaire (Goodman, 1997) and b) the Child Youth Resilience Measure (Jefferies et al., 2019). A triangulation approach is used, combining self-completed questionnaires from students, parents/legal guardians, and teachers to assess the well-being and resilience of children. Bayesian hierarchical models (Gelman et al., 1995) will be used to analyze the impact of covariates on well-being and resilience, providing interpretable results through posterior distributions and handling missing values efficiently.

Healthcare Access and Equity, Regular session – Chair: Jorik Vergauwen – Room K.202

Exploring paradoxes in transgender care: key findings from the “My gender, whose care?” study

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This presentation delves into key finding from the “My gender, whose care?” research project (Das et al., 2023). This project was commissioned by the Dutch Ministry of Health, Welfare and Sport and executed by a transdisciplinary team of researchers from the Radboud University & Radboudumc Nijmegen, the Netherlands.

In this presentation, we will focus on three interconnected paradoxes that elucidate the tension between the organization of care and the changing care demands: *pathologization versus depathologization*; *diagnosis versus exploration*; and *medical care versus society*. These paradoxes operate at multiple levels: individual (micro), interpersonal (meso), and structural (macro) levels.

Trans and non-binary identities are positioned within a medical framework and often pathologized. Despite efforts to shift to non-medical perspectives and to depathologize care, the influence of this framework persists, rooted in the historical medicalization of trans experiences. This dynamic is demonstrated by the shift from Gender Identity Disorder (GID) in the DSM-IV to Gender Dysphoria in the DSM-5. While this shift marks a significant step for depathologization, trans experiences continue to be seen through a medical lens. This pathologization directly causes an increase in registrations and demand for specialized care, as this is often seen as the only place to address gender-related concerns. The results of our mixed-methods, participatory research, demonstrate a crucial issue: trans people have needs that extend beyond specialized care. We refer to this as the paradox of pathologization versus depathologization, demonstrating the tension between diagnosis and the need for individually tailored care trajectories.

From this, a second paradox emerges: diagnosis versus exploration. The current configuration of transgender healthcare is disconnected from the specific needs of trans people. Many trans people desire to explore their gender identity with support of healthcare professionals, but reject the need for a diagnosis. This mismatch leads to dissatisfaction with the healthcare system. Additionally, the long waiting times for accessing care force some trans people to independently discover their needs. Some find support in friends, family, or communities, but others do not have access to this. Educating healthcare professionals beyond the domain of specialized care is essential in order to support trans people in all stages of the healthcare process.

The third paradox, tension between medical care versus society, sheds lights on the intricate interplay between medical care and societal attitudes toward trans and non-binary people. Care seekers currently go to specialist

care centers with questions about their gender identity - care which historically focuses on gender identity and care needs on the level of the individual. However, their care needs are partly determined by their marginalized position in society which may lead to minority stress and experiences of exclusion. We note that currently the psychosocial issues originating from societal challenges are (expected to be) addressed in the medical context. This exemplifies the dilemma of medicalization: without investment in the social aspect of gender diversity, growing waiting lists will persist.

The interplay between medicalization and pathologization has strongly facilitated the development of transgender care. It has also reinforced a binary paradigm of the body and identity formation. This is connected to the notion of social engineering: a framework where medical interventions are logical solutions to better match gender identity and the body. However, this perspective falls short as its emphasis is on binary interventions and disregards interactions with the context.

Our findings show the need for approaches that acknowledge the interplay and interdependence of medical care in conjunction with societal acceptance. We urge interventions to extend beyond clinical settings and to address societal attitudes. This would relieve the burden on specialized care as well as enhance the well-being of trans people and better meet the needs of this community. We essentially prompt researchers to reevaluate and reflect on the current paradigms in which healthcare is being offered and suggest that a more holistic, multilevel, approach can better account for the range of factors that influence transgender people's well-being.

Perceived discrimination in health care in Germany – results of a population survey

Jens Klein (University Medical Center Hamburg-Eppendorf), Olaf von dem Knesebeck (University Medical Center Hamburg-Eppendorf)

Introduction

Although it has been shown that perceived discrimination is associated with adverse health outcomes, research on the experiences of discrimination in health care is sparse. Discrimination can occur on an interpersonal (i.e. discrimination played out between individuals in everyday life) or a structural level (i.e. discrimination by policies, regulations, and constitutional practice) and is associated with certain characteristics (e.g. sex/gender, race/ethnicity, age, socio-economic status (SES), or specific diseases). In a German population survey, the following questions were addressed: How often did people in Germany report having been discriminated in health care due to different reasons, and which socio-demographic groups were most afflicted by perceived discrimination in health care?

Methodology

Analyzes were based on a cross-sectional online survey conducted in Germany in winter 2022/23 by a professional social research institute (forsa). An adult population sample was randomly drawn from a panel which was recruited offline (N=2,201). The sample was weighted by age, sex, education, and federal state according to official statistics. Respondents were asked whether they have ever been discriminated in health care due to the following reasons: age, sex/gender, racism (i.e. migration history, religion, language problems, color of skin), health issues or disability (i.e. overweight, mental illness/addiction, disability), socio-economic status (i.e. income, education, occupation). Furthermore, the following socio-demographic characteristics of the respondents were included into the analyzes: age (18-40 years; 41-59, ≥60), sex, migration background (no, 1st generation, 2nd generation), Income (quartiles), education (four levels based on the CASMIN educational classification).

Results

26.6% of the respondents reported discrimination experiences. Perceived discrimination due to health issues or disability was most frequent (15%), followed by age (9%) and SES (8.9%). Among the health issues, discrimination due to overweight was most frequent (11.3%). Discrimination due to racism and sex/gender was less frequently

reported (4.1% and 2.5%). The summarized indicator of perceived discrimination was significantly associated with all socio-demographic characteristics of the respondents. Younger age groups (especially aged between 18-40 years), women, and 2nd generation migrants (i. e. people who were born in Germany and at least one parent was born abroad) as well as respondents with low income and low education were more likely to report any kind of discrimination in health care. Finally, two groups were found to be at special risk for reporting discrimination in health care across different reasons: women and younger age groups. Discrimination due to racism was more prevalent among respondents who have immigrated themselves than those who were born in Germany but whose parents have immigrated. Discrimination due to SES was significantly associated with (low) income but not with education. Most of the descriptive results were confirmed by fully adjusted regression models showing elevated odds ratios particularly for younger and female respondents as well as migrants.

Conclusions

More than a quarter of the adult population in Germany reported experiences of discrimination in health care. Such experiences were more frequent among lower SES groups, migrants, women, and younger people. Results underline the necessity of interventions to reduce the magnitude and consequences of discrimination in health care. Future studies should apply an intersectional approach to consider interactions between social inequality indicators regarding discrimination and to identify risk groups that are potentially afflicted by multiple discrimination.

The results were limited by using only questionnaires in German language. Thus, discrimination due to language barriers and migration history were potentially underestimated. In terms of measures, self-reports of discrimination experiences were used. Such self-reports can be biased as respondents may perceive or report less or more discrimination than actually exists.

Scarcity in crises – the role of economic, social and cultural capital in accessing covid-19 vaccines in Germany

Laura Goßner (Institute for Employment Research (IAB)), Yuliya Kosyakova (Institute for Employment Research (IAB); Otto-Friedrich-University of Bamberg)

The COVID-19 pandemic generated a high demand for medical goods such as masks, disinfectants, and ultimately COVID-19 vaccines. Until the production of these goods had been sufficiently scaled up and they were available in abundance, their scarcity resulted in questions about a fair allocation. Many governments proposed prioritization systems as a temporary solution. For instance, the German government supported the distribution of free masks to elderly or prioritized certain groups for vaccinations. Prioritizing systems like these are based on core ethical principles. In theory, different values such as equal treatment, favoring the worst-off, maximizing total benefits or promoting social usefulness can be applied (Persad, Wertheimer & Emanuel 2009; Emanuel et. al 2020). The German government stated that the aim of its vaccination prioritization system was to prevent as much death and hospitalization cases as possible (Bundesministerium für Gesundheit 2022). Consequently, individuals were prioritized by age, previous health conditions and employment-related infection risks. Nevertheless, vaccination appointments were for example made through registration platforms and with personal doctors. Apart from the prioritization system, factors like an elaborate personal network to access relevant information, the inclusion into the public health system to know personal doctors, language competencies to use registration platforms for appointments and further factors that vary on the individual level could thus have played a role for the access of COVID-19 vaccines. We therefore ask if the timing of getting vaccinated was dependent on personal resources, which we theorize according to Bourdieu (1986) as individual economic, social and cultural capital. These forms of capital are well-known to not be equally distributed in the society. In particular, recent immigrants and refugees might experience disadvantages in this regard. Given their shorter time span in the receiving country, they often have weaker social networks with fewer connections in the host country. Additionally, they face language as well as structural barriers. We thus analyze which role

economic, social and cultural capital of one's own played in the distribution of COVID-19 vaccines in Germany and whether immigrants and refugees have been consequently disadvantaged.

Empirically, we rely on the newest survey data from the study "Corona Monitoring nationwide (RKI-SOEP-2)", which the Robert Koch Institute (RKI), the Socio-Economic Panel (SOEP) at the German Institute for Economic Research (DIW Berlin), the Research Center of the Federal Office for Migration and Refugees (BAMF-FZ) and the Institute for Employment Research (IAB) conducted in cooperation. All individuals aged 14 and older who participated in the main German Socio-Economic Panel in 2021 were invited to participate in the RKI-SOEP-2 study. This also included individuals from the IAB-SOEP migration sample and the IAB-BAMF-SOEP refugee sample. The field phase of the study began in November 2021 and ended in March 2022, with a total of 11,162 individuals participating. Further information on the study procedure and sample composition can be found in the study protocol (Bartig et al. 2021). The data from the RKI-SOEP-2 study is complemented by longitudinally collected information from previous SOEP surveys. For the paper we use information on individuals' vaccination dates, various factors that represent economic, social and cultural capital and information on an individual's personal preferences of getting vaccinated. The latter is taken into account by considering the factors 'confidence', 'complacency', 'convenience' and 'collective responsibility' known from previous research as part of the 5C model (Betsch et al. 2018) that has been used widely to understand vaccination behavior and preferences.

We firstly conduct a Kaplan-Meier survival analysis to analyze differences in vaccination dates by migration experience. With a survival analysis we are then looking at the role of the prioritization system, personal resources and personal preferences. Lastly, an Oaxaca-Blinder-Decomposition analysis is performed to uncover how much of the difference in vaccination timing between migrants and non-migrants is explained by each factor.

First results from the survival analysis reveal, that on average migrants received their vaccine around one month later than natives. The survival analysis subsequently shows that for example individuals with a higher net household income, those that are employed, those with a bigger circle of close friends or those with higher German language proficiency have been vaccinated significantly earlier. Differences in

Future crises are likely to be characterized by the scarcity of a good, service or material resource again. We shed light on factors that cause a disadvantageous starting point in such a competition. We conclude that if such factors are not considered when designing prioritizing systems, some groups will consequently be more severely affected by crises such as the pandemic and health inequalities could be exacerbated further. As the governmental efforts aim at preventing inequalities, this paper will provide guidance for similar future situations.

Towards diversity inclusion in adolescent healthcare: A theoretical model of LGBTQ+ inclusive school nursing

Minna Laiti (university of Helsinki), Sanna Salanterä (University of Turku)

Introduction

School health services, including school nursing, are globally recognized as a unique opportunity to reach adolescents, provide primary health care and comprehensive health promotion to them. School nurses play a pivotal role in school environment. As health professionals, they follow students' development, growth, and health, and adolescents can discuss with them various health topics such as sexuality. However, LGBTQ+ youth are known to be a vulnerable minority group in healthcare, who have specific health disparities compared to their heterosexual and cisgender peers. The health disparities are linked to discrimination, marginalization, and intolerance based on sexual orientation and gender identity, that many LGBTQ+ youth are still experiencing.

In health research, studies on LGBTQ+ youth are scarce. The existing research shows that health professionals still lack knowledge and skills to provide care to LGBTQ+ youth, and that LGBTQ+ youth are having unmet health and support needs. Furthermore, no previous research has focused on LGBTQ+ youth in secondary school nursing, or explored what elements are needed to create LGBTQ+ inclusive secondary school nursing.

Methodology

The aim of the study was to develop a theoretical model describing LGBTQ+ inclusive secondary school nursing. The study comprised three types of qualitative data, which were integrative literature review, the experiences of Finnish LGBTQ youth on secondary school nursing, and the perceptions of Finnish secondary school nurses on supporting LGBTQ+ youth. The qualitative data constituted the empirical knowledge for a theoretical model, and the structure of the model was based on Chinn and Kramer's the theory of fundamental patterns of knowing in nursing (emancipatory, ethical, empiric, aesthetic, and personal).

Results

LGBTQ+ inclusive secondary school nursing is a multidimensional reality, in which school nurse's knowledge, skills, attitudes, and values are combined with their reflective thinking as a health professional. Emancipatory knowing presents the awareness of inequalities faced by LGBTQ+ youth and ways to reduce inequalities, ethical knowing presents the ethical and moral considerations and actions in providing care for a vulnerable minority group, empiric knowing presents evidence-based LGBTQ+ inclusive nursing knowledge, education, and competence to use them in practice. Aesthetic knowing presents school nurse's acknowledgment of the uniqueness of LGBTQ+ youth and flexibility in creating safe and confidential atmosphere in their practice, and finally personal knowing presents school nurse's inner awareness of themselves and their relationship with LGBTQ+ youth.

Conclusions

LGBTQ+ youth has been identified as a vulnerable minority group in healthcare, but research and actions to recognize and meet their health and support needs are limited. Theoretical model of LGBTQ+ inclusive secondary school nursing offers novel research-based knowledge about how LGBTQ+ inclusiveness is a multidimensional reality. In this reality, school nurses do not only need LGBTQ+ inclusive information and education, but they also need to be aware of the vulnerability and uniqueness of LGBTQ+ youth, how to be ethically and morally responsible school nurses, and how to create their practice confidential and safe space. In future, more research is needed on how the theoretical model could be implemented to school nursing practice and guidelines, and how LGBTQ+ youth and school nurses perceive its applicability in order to achieve equal and equitable health outcomes to LGBTQ+ youth.

Intersectionality and Syndemics: Theoretical and Methodological Challenges, Thematic Session – Chair: Philippe Bos – Room K.203

Engaging people experiencing socioeconomic deprivation in qualitative research: Reflections from participants and researchers

Abi Woodward (University College London), Megan Armstrong (Queen Mary University London)

Introduction

People experiencing socioeconomic deprivation (PESD) have a higher prevalence and increased severity of long-term conditions (LTCs) compared with those from more affluent backgrounds. PESD are also less likely to actively engage in research to share their lived experience. To avoid worsening health inequalities and maintaining the status-quo, researchers must engage more efficiently with underserved populations. Focusing on a UK context, the need for change is evident, and it is imperative that researchers explore innovative and efficient ways to engage with these underserved populations. Socioeconomic deprivation extends well beyond financial aspects and while it is easy to focus solely on economic factors, the lived experiences of PESD are multidimensional. As

such, individuals who experience socioeconomic deprivation often face a multitude of barriers to healthcare services, including but not limited to lack of financial resources, lack of access to education, lack of digital skills, lack of social capital, housing instability and discrimination.

The aim of this presentation is to offer methodological insights into our journey and promote qualitative health research that truly encompasses the experiences of PESD. We will focus on sharing and reflecting, from researcher and PESD perspectives, the challenges faced and how these were overcome in recruitment, conducting interviews, and meaningful engagement with a Public Advisory Group (e.g., members of the public who contribute to research through their own lived experience). We will also share some of our co-designed visual outputs.

Methodology

We used several techniques to engage PESD in health research in the UK: 1), developing active partnerships with a Public Advisory Group; 2), engagement workshops to explore ways of overcoming under-representation of PESD in health research; 3), co-design of creative outputs; and 4), recruitment of 40 participants into a qualitative health study in 2022/23 where semi-structured interviews were conducted and data analyzed using a reflexive thematic approach.

Results

We found experiences of socioeconomic deprivation extends well beyond financial aspects, meaning many barriers to healthcare can be overlooked by researchers. Recognizing the value of public contributors was a vital part of our research and we worked with our Public Advisory Group to develop a set of statements for potential participants to self-identify with. Engagement with voluntary and community sector (VCS) organizations also enabled us to explore barriers to research participation from a different perspective. We learned about the importance of investing time to build good working relationships between academia and the VCS, where others have gone wrong in the past and how we can avoid these mistakes in the future. Another critical lesson that we learned was that research findings seldom reach underserved populations. Traditional dissemination methods often fail to engage beyond academic audiences. Creative outputs acted as a bridge between the academic realm and the communities they serve.

Conclusion

Exploring socioeconomic deprivation in qualitative research requires an intersectional approach, as focusing on individual identity characteristics, runs the risk of over-simplifying the complexities surrounding health inequalities. Throughout our research journey, we encountered challenges and learnings at every step, from recruitment, to conducting interviews, and engagement with public contributors. Central to our success was the establishment of meaningful partnerships with a diverse Public Advisory Group and representatives from the VCS. Building such partnerships requires substantial time investment from researchers, which often goes against funders focus on 'value for money' projects. Our experiences demonstrate that while change is possible, it requires a commitment to innovation, perseverance, empathy, and inclusivity.

The HIV-tuberculosis-stigma syndemic and its impact on the use of occupational tuberculosis screening and treatment in South African hospitals.

Edwin Wouters (university of Antwerp), Michelle Engelbrecht (University of the Free State), Gladys Kigozi-Male (University of the Free State)

Introduction

Tuberculosis (TB) has become an occupational health hazard in South African hospitals where healthcare workers (HCWs) are additionally confronted daily with HIV and its associated stigma, causing a syndemic. Early TB diagnosis and treatment are vital, but the uptake of these services through occupational healthcare units (OHUs) is low. The current study hypothesizes that (1) the link between HIV and TB and (2) the perceived HIV

stigmatization by colleagues create (3) a double HIV-TB stigma which increases (4) internalized TB stigma and leads to (5) a lower willingness to use OHU services for TB screening and treatment.

Methods

A cross-sectional study using the baseline data from the HIV and TB Stigma among Healthcare workers Study (HaTSaH Study). Setting Six hospitals in the Free State province of South Africa. Participants 820 HCWs of the six selected hospitals.

Results

The study results demonstrate that the co-epidemic ($\beta=0.399$ (screening model) and $\beta=0.345$ (treatment model)) combined (interaction effect: $\beta=0.133$ (screening) and $\beta=0.132$ (treatment)) with the persistent stigmatization of HIV is altering the attitudes towards TB ($\beta=0.345$ (screening) and $\beta=0.400$ (treatment)), where the stigmatizing views of HIV are transferred to TB-illustrating the syndemic impact. Our model demonstrated that this syndemic not only leads to higher levels of internal TB stigma ($\beta=0.421$ (screening) and $\beta=0.426$ (treatment)), but also to a lower willingness to use the OHU for TB screening (probit coefficient=-0.216) and treatment (probit coefficient=-0.160). Confidentiality consistently emerged as a contextual correlate of OHU use.

Conclusions

Theoretically, our results confirm HIV as a 'syndemic generator' which changes the social meaning of TB in the hospital context. Practically, the study demonstrated that the syndemic of TB and HIV in a highly endemic context with stigma impacts the intended use of occupational TB services.

Using creative and participatory I-Poems to explore intersectional stories of health and illness among Roma women living in northern England

Lois Orton (University of Sheffield), Olga Fuseini (University of Sheffield)

Introduction

This is a reflective piece, exploring the use of creative and participatory I-Poems to foreground the stories of health and illness experienced by Roma women living in northern England. Roma women experience some of the worst health and social inequalities in the European region, with life expectancies as much as 20 years below the national average. These inequalities are underlined by the compounding of many layers of discrimination based on race, gender and class. Our Wellcome-funded project 'Roma Health Stories' aims to explore in depth the intersections of these experiences and how they shape the health journeys of Roma women living in northern England (and, in a separate arm of the study, the Czech Republic). A key aim of the project is to share the Roma women's emic understandings of their own journeys.

The I-Poem (developed by Carol Gilligan) allows researchers to explore how a research participant speaks, thinks and feels, staying as close as possible to the participants' voicing of themselves, before overlaying this with research categories and concepts. It is a way of really listening and therefore hearing the complex details of a person's story. As such, we believe the I-Poem holds promise as a way of understanding the intersections of racism, sexism and poverty that our study participants experience on a daily basis. However, with traditional I-Poems, much of the task of identifying and extracting the key parts of an individual's narrative is left with the researcher. Reflecting the creative and participatory turn in sociology, and our underlying ethos of co-production and openness, we were keen to use I-Poems as a means of collaborating with our participants to creatively produce a shared representation of their multi-layered stories. This abstract details our experiences in doing so.

Methodology

Initially, we conducted two-stage life history interviews with 10 Roma women living in northern England. We then followed an adapted two-stage version of the traditional I-Poem approach.

Stage one For each participant, we read through the transcripts relating to their interviews and highlighted the use of the first person 'I' and the seemingly associated text. We then lifted the I-phrases out of the transcript and pasted them into a new document in the sequence they appeared in the original transcript(s). Finally, we arranged the text into stanzas based on different topics and voices. The two project researchers (Orton and Fuseini) worked together to create the poems, checking and challenging each others' constructions.

Stage two Once an I-Poem had been created we then presented the text to the participant and read it aloud to them. We discussed:

- After reading through the poem, what are your general thoughts?
- How accurately do you feel the poem captures your thoughts/experiences?
- What could be added to the poem to capture your experiences better?
- If there is anything you would like removed, what would that be and why?

Discussions were audio-recorded (with permission) and field notes of observations were taken. Following these discussions, participants were provided with a few print-outs of the poem as well as cardboard, scissors, pencils and crayons, and were encouraged over the following two weeks to rearrange the text (removing/editing sections they did not agree with and adding new ones) and to visually enhance the poem with illustrations, doodles, etc, to depict important people and places referred to in the poem.

Results

Participants enjoyed the opportunity to create their own I-Poem. Whilst most did not greatly challenge the content, the process of discussing and allowing them to embellish the poem facilitated the sharing of a much greater richness of experience. The visual elements greatly enhanced the verbal/textual material, adding depth and a strong sense of personality to each poem.

There are some limits in the use of I-Poems, particularly in social research that is concerned with the collective as well as the individual experience. However, we felt that the method did allow for the inclusion of broader processes and relational aspects of people's lives. We also see the poems as a starting point to distil richly detailed individual stories, before then exploring common processes across the poems/stories (through subsequent group methods).

The women took ownership of their poems. Ultimately they belong to them. The 'Roma Health Stories' project is simply borrowing them. Over the coming months the poems will be used at various community festivals and policy/practice and academic events to bring to life the key messages that we and the participants want to share from the research.

Conclusion

Creative and participatory I-Poems, can form a useful tool, and potentially a powerful output, when used as part of a broader social analysis of intersectional processes leading to/from health and social inequality.

Concepts and definitions of healthy ageing: A systematic review and synthesis of theoretical models

Marilyne Menassa (University of Bern; UMC Utrecht), Katrien Stronks (University of Bern), Farnaz Khatmi (University of Bern; Tehran University of Medical Sciences), Zayne Milena Roa Diaz (University of Bern), Ocatvia Pano Espinola (University of Bern; University of Navarra), Maga Gamba (University of Bern), Oche Adam Itodo (University of Bern; Swiss Paraplegic Research), Chepkoech Buttia (University of Bern), Faina Wehrli (University of Bern), Beatrice Minder (University of Bern, University Library of Bern), Minerva Rivas Velarde (University of Geneva), Oscar H. Franco (University of Geneva)

Background

Healthy ageing (HA) has been defined using multiple approaches. We aim to produce a comprehensive overview and analysis of the theoretical models underpinning this concept and its associated normative terms and definitions.

Methods

We conducted a systematic review of peer-reviewed HA models in Embase.com, Medline(Ovid), Cochrane CENTRAL, CINAHL, PsycINFO, and Web of Science until August 2022. Original theoretical papers, concept analyzes, and reviews that proposed new models were included. Operational models/definitions, lifespan development psychology theories and mechanisms of ageing were excluded. We followed an iterative approach to extract the models' characteristics and thematically analyze them based on the approach of Walker and Avant. The protocol was registered in PROSPERO(CRD42021238796).

Findings

Out of 10,741 records, we included 59 papers comprising 65 models/definitions, published in English (1960-2022) from 16 countries in Europe, Asia, and America. Human ageing was described using 12 normative terms, mainly (models (%)): successful (34 (52%)), healthy (eight (12%)), well (five (8%)), and active (four (6%)). We identified intrinsic/extrinsic factors interacting throughout the life course, adaptive processes as attributes, and outcomes describing patterns of ageing across objective and subjective dimensions (number of models/definitions): cognitive(62), psychological(53), physical (49), social (49), environmental (19), spiritual (16), economic (13), cultural (eight), political (six), and demographic (four) dimensions. Three types of models emerged: health-state outcomes (three), adaptations across the life course (31), or a combination of both (31). Two additional sub-classifications emphasized person-environment congruence and health promotion.

Conclusion

HA is heterogeneously termed and conceptualized multidimensionally as adaptive processes of dynamic person-environment interactions to ageing, health-state outcomes, or both. Congruence with the living environment and health promotion/empowerment are emphasized. Our model classification provides a basis for harmonizing conceptual terms and dimensions that can guide research and comparisons of empirical findings. This would inform social and health policies enabling HA for populations in various contexts.

Health crisis, Changing Roles and Social Capital: An intersectional study in Uttar Pradesh and Goa

Swayamshree Mishra (IIT Kanpur), Charumita Vasudev (Lancaster University), Ankita Rathi (Lancaster University), Jasmine Fledderjohann (Lancaster University), Sukumar Vellakkal (IIT Kanpur)

Introduction

In this paper we examine the intricate nexus between healthcare challenges, changing individual and family roles and identities, and social capital as responses to health crises in the India states of Uttar Pradesh and Goa. We analyze the narratives of families with at least one member in the household facing health challenges in the past three years to comprehend how these families navigate the multi-faceted daily challenges – social, economic and psychological - associated with abrupt and persistent health-related issues within families. Our interest lies in changing dynamics within families as a reaction to health challenges, and the impacts of these changes on other elements of well-being like food access, dietary habits, and education.

We use intersectionality as a theoretical and methodological tool to examine each of the narratives, constructing a social context to understand not just intra-household dynamics but also to explore whom individuals and families turn to, the specific circumstances prompting such outreach, and the consequences of seeking support from one's social network. While our primary interest lies in uncovering the mediating role of social networks and social capital in these circumstances, we also prioritize examining their repercussions and the decision-making process behind them.

Methodology

This study is part of a larger mixed-methods study on food insecurity in the Global South. We draw on primary qualitative data collected through semi-structured interviews in 87 households in rural and urban parts of Uttar Pradesh and Goa between December 2022 and March 2023.

Goa is the smallest state in India, recognized for its thriving tourism sector and comparatively higher socio-economic status. Migration patterns are influenced by tourism related opportunities, with most number of inter-state migrants arriving in Goa from neighboring states of Karnataka and Maharashtra (Census, 2011). Uttar Pradesh is India's most populous state with majority of people living in rural areas. Migration is common, often driven by agrarian distress and pursuit of better employment opportunities, particularly from rural to urban areas.

Our field team of three female interviewers interviewed multiple members (aged 7+ years old) of each household (in Hindi) on topics around food, nutrition, debt, health challenges, and Covid. We aimed to maximize sample diversity by caste, family and household structure, religion, and occupation. We use thematic analysis to understand how different members of the same household approach and make meaning of the health-related challenges the household has experienced.

Results

We argue that responses to health crises and the engagement with social networks are strongly shaped by the interplay of various intersecting identities such as age, status within family, caste, gender, class, race, neighborhood, and religion of individuals and families.

Some of the preliminary emerging themes explore how health related challenges can turn out to be significant life-altering events that prompt a revaluation of one's social standing and identity within the household and community. Moreover, these challenges have the capability to reshape traditional dynamics of trust formed within social capital.

Another theme emerging from our analysis revolves around the profound influence of religious and caste identities on health-related crises. This is evident in certain narratives related to the Covid pandemic. We also explore the gendered burden during a health crisis and gendered access to social capital in the Indian context. Narratives from the field show how women may encounter obstacles in establishing networks, thereby affecting their access to resources and opportunities.

Conclusion

While scholars have explored the protective influence of social network and social capital on health, less explored are the consequences of seeking and providing help and its impact on existing identities. This paper is an important addition to extant literature exploring the relationship between social capital, health, and identities. Further by using an intersectional lens we emphasize the need for a nuanced understanding of how multiple social identities such as caste, gender, race, age and class intersect. By using this approach we highlight the unique challenges and opportunities faced by individuals and their families, emphasizing the complexity of social interactions and their impact on existing identities. It adds depth by revealing how various dimensions of social identity intersect to shape access to resources, influence social networks, and ultimately impact health disparities within diverse populations in India.

3 July: 15:30 – 17:00

Healthcare Access and Equity, Regular Session – Chair: Jorik Vergauwen – Room K.101

Development of a measurement instrument for a broad approach of health

Mirte Boelens (Leiden University Medical Center), Cheryl Roumen (Maastricht University), Esther J. Bloemen-van Gorp (Zuyd University of Applied Sciences; Fontys University of Applied Sciences), John Dierx (Avans University of Applied Sciences), Lenny Nahar-van Venrooij (Jeroen Bosch Hospital), Tim van Zutphen (University of Groningen), Jaron Schnitzer (Fontys University of Applied Sciences), Elske van den Akker-van Marle (Leiden University Medical Center), Miriam J.J. de Kleijn (Institute for Positive Health), Marja van Vliet (Institute for Positive Health), Jessica C. Kiefe-de Jong (Leiden University Medical Center), Marieke D. Spreeuwenberg (Maastricht University)

Introduction

The concept of health is changing, where health encompasses not only physical, mental and social dimensions, but also resilience, meaningfulness and daily life aspects. Currently, no valid measurement instrument exists that captures these dimensions of health. The aim of this study was to develop a measurement instrument within care, social domain and public health.

Methodology

Based on the previously developed Context-sensitive Positive Health Questionnaire (CPHQ), nine focus groups were organized with different stakeholders, e.g. (para)medics, policy makers, citizens, researchers, and patients. Thematic qualitative analysis and an adapted quantitative Delphi consensus method was used leading to a preliminary measurement instrument. Items were categorized according to the Capability Approach, validated with experts and verified with a member check.

Currently, a longitudinal study in a general population is conducted with three measurement moments. In this study, the population is representative for age, sex and social-economic status. To adequately compare the CPHQ, validated questionnaires such as the EQ5D-5L. In the first measurement moment, there will be approximately 1000 respondents. We will analyze the construct validity and internal consistency by confirmatory factor analysis and we will examine the discriminant validity. After this longitudinal study, the responsiveness of the CPHQ will be examined in several prospective intervention studies within diverse health and wellbeing domains.

Results

The previous CPHQ consisted of 32 items. The focus groups resulted in maintaining 10 items, adjusting 21 items and removing 1 item. After the expert sessions and member check, 23 items remained related to topics such as trust, acceptability and resilience. Most striking agreements between focus groups were the importance of the items “I feel healthy” and “I feel happy”, avoiding examples or normative words such as “adequate” and avoidance of political items. Most discussion concerned items related to money and relaxation as necessary items to measure health.

Preliminary results of the longitudinal study that is currently conducted are expected in April. Preliminary results of the prospective intervention studies are expected 2025.

Conclusion

Most of the CPHQ items were considered relevant and feedback on items was often similar across stakeholders. The second version of the 23-item CPHQ is currently being validated and tested among a panel and in longitudinal studies.

A valid, reliable and responsive measurement instrument for a broad health approach ensures a multidimensional perspective on perceived health unified in one tool. The broad consortium and co-design with various stakeholder groups and end-users will lower the threshold for adoption and national implementation within care, social domain and public health.

Exploring lived experience of barriers to accessing medicines

Pauline Norris (University of Otago), Shirley Keown (Turanga Health), Vanda Symon (University of Otago), Molly George (University of Otago), Sandhaya (Sandy) Bhawan (Pharmac- Te Pataka Whaioranga; Royal New Zealand College of General Practitioners), Rose Richards (University of Otago), Lauralie Richard (University of Otago)

Introduction

Ethnic and other inequities in access to medicines have been documented in New Zealand, and a range of potential barriers to access identified. These include affordability, lack of transport, geographical distance, and acceptability of services. Existing research has tended to focus on one barrier, rather than how barriers interact and intersect, and how they are experienced by consumers.

Methodology

We carried out a longitudinal qualitative study to explore lived experience of access to medicines. We recruited 21 households from groups that may be at risk of poor access (Māori, Pacific, former refugee, Pākehā (New Zealand European) on low incomes). Households were eligible if their members mainly belonged to one of these groups and someone in the household took medicines regularly. Participants were recruited through community organizations and networks, and healthcare providers. For example, one participant was recruited at a food bank, one through a service for former prisoners, two were recruited through community pharmacies, and primary health organizations assisted in contacting refugee participants. We followed participating households for approximately 12 months, with repeated interviews, phone conversations, text messages and observations. We asked about people's lives and how things were going, focusing on healthcare and medicines, within the context of people's lives.

Results

Many of our participants faced social disadvantage and had physical health problems. Some also had mental health problems. Often their lives were characterized by a sense of "too much going on" and this formed the backdrop to issues with medicines. Obtaining required medicines was just one of many issues to be faced.

There were many affordability problems: most participants had to pay to obtain a prescription from a general practitioner (either by visiting or ordering a repeat prescription), as well as prescription charges. It was clear that charges could directly prevent access, but also potentially eroded relationships with healthcare providers, reducing acceptability of services. There could be confusion about charges, and when they were perceived as unreasonable participants felt aggrieved. At the time of the study, most pharmacies charged a fee for collecting medicines, and this drove some participants' choice of pharmacy. Some felt forced to choose between cost and physical accessibility or quality of care.

Refugee participants faced significant barriers: they were unfamiliar with and dissatisfied with healthcare in New Zealand, faced seemingly insurmountable communication barriers, and many did not trust the medicines they were prescribed. Despite the presence of an interpreter in general practice consultations, there were many misunderstandings and some refugee participants felt they were treated badly because of their refugee status. Interpreters were not available in pharmacies, meaning refugee participants could not ask questions about their medicines or discuss any concerns.

Many participants experienced mistakes in the ordering or dispensing of their medicines, and the responsibility for sorting these out fell on participants. This took time and energy which participants did not always have.

Conclusions

Our results provide insight into overlapping and interacting barriers to medicines access faced by people experiencing social disadvantage in New Zealand. Since the study, affordability has improved somewhat with the elimination of some prescription charges, but many other barriers remain.

Navigating Diabetes Care Inequities: An observational study on the effectiveness of the Chronic Care Model for improving quality of care for type 2 diabetes patients in Belgium

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Introduction

Type 2 diabetes (T2D) is one of the fastest-growing public health challenges, with current health systems unable to meet the needs of those affected. The concept of integrated care is proposed as a solution to improve the quality of care for chronic conditions such as T2D. The Chronic Care Model (CCM) materializes integrated care, providing guidance on how healthcare systems should be designed and organized to deliver high-quality chronic care (Wagner, 1998). According to Donabedian's landmark model (1988), however, quality of care entails three dimensions: it is not only related to the structure (i.e. the organization of care), but also to the process and intermediate outcomes of care. Hence, it is relevant to examine whether the implementation of the CCM in primary care practices is also associated with an improved process and intermediate outcomes of T2D care. This brings us to the two-fold objective of the current study:

1. To study the impact of the implementation of the CCM on both process and outcome quality indicators (QIs) of T2D care.
2. To assess whether this impact differs for socio-economic vulnerable and non-vulnerable patients.

Methods

We developed a unique longitudinal database that combines (a) self-collected data on the structure of T2D care at the level of primary care practices (i.e. the degree of implementation of CCM), with (b) health insurance data and (c) medical lab data, measuring the process and outcome QIs of T2D care, respectively (see table 1). Our probability sample consists of a cohort of 7593 T2D patients aged 40+ from 58 primary care practices in three regions in Flanders (Ghent, Antwerp and the Campines) who were retrospectively followed-up on a yearly basis for the period 2017 to 2019. Medical lab data was obtained for a subsample comprising 59.7% of our initial cohort of T2D patients (n = 4565).

In our analysis, we have four dependent variables measuring the quality of T2D care: two process and two outcome QIs. As regards the former, we measure whether for a given patient at least 2 HbA1c measurements and one LDL-cholesterol (LDL-C) measurement was performed in the past year. As regards the latter, we measure the patient's yearly average HbA1c and LDL-C levels. The independent variable of primary interest measures the degree of implementation of the CCM in the participating practices.

A series of logistic (for the binary process QIs) and linear (for the continuous outcome QIs) mixed-models were estimated to 1) assess the main effect of the implementation of the CMM on the process and outcome QIs and 2) to assess the cross-level interactions of the implementation of the CCM with socio-economic vulnerability. The mixed-models have a three-level structure, with repeated observations nested within patients, which are, in turn, nested within practices.

Results

More than 15% of the observed variation in the process QIs was due to systematic differences between primary care practices, suggesting a substantial contextual effect of primary care practice characteristics on the process

of T2D care. The degree of implementation of the CCM was positively associated with both process indicators: T2D patients had higher odds of being appropriately followed-up regarding HbA1c and LDL-C measurements in practices that implemented the CCM to a higher extent. In addition, socio-economic vulnerable patients were less likely to be followed-up appropriately regarding HbA1c measurements. We found, however, a stronger positive relationship between the CCM and the HbA1c process indicator for socio-economic vulnerable patients, so that the equity gap in HbA1c follow-up was smaller in practices that scored higher on the implementation of the CCM.

In contrast, for the outcome QIs, we found that the variation in HbA1c and LDL-C levels was attributed almost entirely to differences between individuals and changes within individual over time. Only a negligible proportion was due to systematic differences between practices, suggesting that individual rather than practice characteristics are more important in determining HbA1c and LDL-C levels of patients. Unsurprisingly then, no relevant impact of the implementation of the CCM was found on the outcome QIs.

Conclusion

This observational study shows that practices' higher degree of implementation of the CCM is associated with an improved T2D care process, but not with better intermediary patient outcomes. Moreover, this study demonstrated the effectiveness of the CCM in reducing the healthcare inequity gap regarding adequate HbA1c testing.

Disrupting healing: Experiences of ophthalmic clinics by vision impaired people living in Southwest England

Rebecca Woods (University of Plymouth)

Introduction

Marie: "I don't like the Eye Infirmary they are *horrible* down there. They just seem, I don't know. It's not like any other section of the hospital."

The problem being studied is the detrimental impact of ophthalmic clinical practice on vision impaired people in Southwest England. From my doctoral study and professional practice, I know that residents with vision impairment in Southwest England are very rarely included in vision impairment research. Broadly, vision impairment research can be divided into ophthalmic research and rehabilitative research. This study is addressing gaps in vision impairment rehabilitative research. One existing ophthalmic study examines prevalence of vision impairment certification, (Savage, Claridge, & Green, 2018), whilst ophthalmic studies involving Bristol Eye Hospital predominantly explore pharmaceutical and surgical developments, or prevalence of particular optical conditions.

Key intersectional markers for this group are vision impairment and rural locations, combining to affect individuals' experiences of clinical appointments in unique ways (Imrie & Edwards, 2007; McManus & Lord, 2012). The term 'remaining vision' indicates that a participant is able to see something, whilst the term 'blind' refers to people with no optical vision. Four participants have remaining vision, whilst four are blind. Each participant's recollections are catalysts for change. By presenting strong critiques of regional ophthalmic clinics in Southwest England from participants, this study draws attention to inequalities between medical specialties. Solutions that make use of VIPs' living expertise to more closely link clinical practice with vision impairment rehabilitation, will be shared. My research found that accurate information sharing, alertness to rural living, and intelligent compassion need to become more evidently embedded in the diagnostic and treatment pathway of ophthalmology.

Methodology

Relational sociology is my ontology (Gergen, 2011) combined with an interpretivist epistemology (Smith, Flowers,

& Larkin, 2009). The research is rooted in phenomenological understanding, emphasizing tool-use and human embodiment (Merleau-Ponty, 1945/2014). This study is conducted in an experiential, community-based educational context. My researcher positionality as a Rehabilitation Officer with people with Vision Impairment, (ROVI) is my professional context, with my professional migration from suburbia to rurality shaping my approach.

The study obtained ethical approval from the University of Plymouth and the local authority where interviews took place. Eight participants were purposively recruited, via professional and informal social networks.

Innovative semi-structured, multi-sensory interviews using objects foreground the senses (Høffding & Martiny, 2016). The interview method combines serious academic intent with playful creativity. This interview method is an adaptation of Z-MET (Zaltman & Coulter, 1995). Objects are catalysts for conversational exchanges and embodied responses in the full human sensorium (Duncum, 2012). The selection includes daily household tools, aromatic oils, and a greeting card with sound. Eight questions, covering turning points, relationships, and day-to-day interactions provide additional scope. Prioritizing of senses in daily life connects this study with sensory ethnography (Pink, 2015).

Results

Following analysis, six group themes are defined. The most relevant to clinical experiences is Light and Sound, as each participant with remaining vision describes how artificial light can enhance or reduce functional vision and blind participants articulate the centrality of acoustics, touch and smell for them.

All participants with remaining vision speak strongly about ophthalmic clinics. Their recollections and observations are expressed with passion, frustration, anger, and incredulity. Three out of the four blind participants narrate respective life-changing experiences of ophthalmic surgery and follow-up appointments, some of which occurred decades ago. The chronologically distant recollections provide sources for comparing contemporary ophthalmic practices. The rural locations of their homes contribute towards alienation from medical monitoring. This research identifies and conveys participants' living expertise in their daily lives, a dynamic contrast to their passivity as ophthalmic patients.

The intersecting of vision impairment and living in a rural location has multiple consequences for participants. Practical impacts of costs and time involved in travelling from rural locations versus the lack of immediate benefit from ophthalmic appointments. Clinical appointments are short and held indoors, whilst many rural residents spend a great amount of time outside. Specific challenges of living in a rural home are not considered when defining clinical priorities. Decisions are predominantly based on biological parameters, reducing social factors such as rural isolation, age, ability to use alternative reading methods or internet-based technologies. Living in a rural location reduces opportunities to connect with patient support groups especially if these meet at hospital, city, or market town locations.

Conclusion

This research shows how ophthalmology appointments and time spent as in-patients, are intensely powerful experiences. To spread rehabilitative reasoning more effectively, I suggest offering Rehabilitation Mentoring and Coaching in ophthalmic clinics. The mentors and coaches would have to be people with vision impairment, with their own living expertise building credibility with patients. This service would link surgical expertise with rehabilitative skills and consider patients as future living experts.

Unconscious bias among health professionals

Ursula Meidert (Zurich University of Applied Sciences), Godela Dönniges (Zurich University of Applied Sciences), Thomas Bucher (Zurich University of Applied Sciences), Frank Wieber (Zurich University of Applied Sciences), Andreas Gerber-Grote (Zurich University of Applied Sciences)

Introduction

Although the professional ethos of health care providers includes treating all people equally regardless of their physical and mental characteristics, there are inequities between groups of people in health care (James, 2017; Maina et al., 2018). Numerous factors contribute to health disparities between groups of people, such as poverty, low health literacy, and harmful health behaviors (Ho & Lawrence, 2021). However, disparities still remain when confounding variables related to patient access, such as income and health insurance, are controlled for (Artiga et al., 2020; Ho & Lawrence, 2021). One factor contributing to these disparities may be explained by unconscious biases in health care provider perceptions (Green et al., 2007; Nelson, 2002; Smedley et al., 2004). The term “bias” is used to describe a tendency to favor one group over another (Marcelin et al., 2019). It often involves associating physical features or characteristics with a particular behavior (FitzGerald & Hurst, 2017; Groves et al., 2021; James, 2017), i.e., categorization. Unconscious bias is described as involuntary associations or attitudes that influence our perceptions and thus our behavior, decisions, and interactions in an unconscious manner (e.g., (FitzGerald & Hurst, 2017; Hall et al., 2015; Maina et al., 2018; Marcelin et al., 2019; Mulchan et al., 2021). It is believed that implicit biases are learned through cultural immersion and socialization (FitzGerald & Hurst, 2017). Hence, health professionals may harbor unconscious prejudice against individual patients or patient groups due to their age, race, gender or other factors without their conscious knowledge or intention. Much research has been conducted in recent years on the subject with mixed results. This review intends to give an overview of the literature that has emerged during the last 10 years.

Methodology

A scoping review was conducted using the PCC framework. Five databases were systematically searched: PubMed/MEDLINE (through PubMed), PsycINFO, PsyArticles, AMED through OVID and CINAHL through EBSCOhost in January 2022. All records were double screened and were included when they were concerned with the unconscious bias in trained health professionals, published between 2011 and 2021 in English, German, or French. Results were extracted into a structured table.

Results

The search resulted in 5186 records, of which 300 were duplicates. After the title and abstract screening, 4210 records were removed and another 19 studies from reviews were added. We conducted a full text screening with 695 records after which 87 articles from 81 studies remained.

The findings indicate that there are many studies from around the globe that address different types of biases and use different methods as well as samples. Studies originated from North America (n=60), Europe (n=13), and the rest of the world (n=6). 107 biases were assessed with implicit measures or vignettes or both. Ethnic bias was investigated most frequently (n=46), followed by gender bias (n=11), weight bias (n=10), socio-economic status bias (n=9), and mental illness bias (n=8). Other implicit biases assessed are directed against age, LGBTQ people, and people with disabilities.

The results suggest that unconscious biases from health care providers towards their patients seem to be widespread. Almost all studies using an implicit measure observed implicit biases in health professionals (53 out of 55). 75 % of studies using the vignette method reported an unconscious bias (33 out of 44) against patients.

Although implicit biases were found in all health professions, most studies were conducted with physicians (51 studies) or nurses (20 studies) while other health professionals were only sporadically studied or subsumed under “health care providers” or “other health care providers”.

Conclusions

Most health professionals assessed in the studies included in this review have an unconscious bias against certain groups of patients. There are some challenges in the conceptualization of the unconscious bias, the terminology used, and the use of instruments. Ethnic biases in physicians and nurses in the United States are well-confirmed.

Research is missing on other biases, from other regions of the world (Europe), and amongst other health professions.

Cultural Capital and Food-Related Practices, Thematic session – Chairs: Thomas Abel & Gerry Veenstra – Room K.102

Do economic, social, and embodied cultural capital interact in relation to fruit and vegetable consumption?

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Background

Although Bourdieu's capital theory emphasized that economic, social, and embodied cultural capital interact to shape health behavior, existing empirical research mainly considered separate associations of the three forms of capital. Our aim was to investigate if and how economic, social, and embodied cultural capital are conditional on each other in their associations with adults' fruit and vegetable consumption.

Methods

Cross-sectional, self-reported data from the 2014 GLOBE survey of 2812 adults aged between 25 and 75 years residing in Eindhoven, the Netherlands were used. Step-wise multiple logistic regression models included economic, social, and embodied cultural capital and adjustment for potential confounders. The models estimated odds ratios of main effects and two-way interactions of the forms of capital with fruit consumption and vegetable consumption.

Results

In the main effects models, embodied cultural capital was consistently positively associated with all outcomes. Social capital was positively associated with fruit consumption and vegetable consumption, and economic capital was positively associated with vegetable consumption. In the two-way interaction models, none of the combinations of the forms of capital were conditional on each other in relation to fruit or vegetable consumption.

Conclusion

Embodied cultural capital had a strong, positive association with both fruit and vegetable consumption, but its association was not conditional on other forms of capital. This may show that embodied cultural capital operates distinctly from economic and social resources. Policies that take differences in embodied cultural capital into account, or (environmental) changes that dampen the importance of embodied cultural resources for health behavior, may help increase fruit and vegetable consumption.

Exploring the relationship between non-declarative cultural capital and food-related practices

Joost Oude Groeniger (University Medical Center Rotterdam; Erasmus University Rotterdam), Willem de Koster (Erasmus University Rotterdam), Tim van Meurs (University of Amsterdam), Kjell Noordzij (Erasmus University of Rotterdam), Julian Schaap (Erasmus University of Rotterdam), Jeroen van der Waal (Erasmus University of Rotterdam)

Introduction

Bourdieuian class analysis offers an important theoretical framework to explain how the unequal distribution of non-monetary resources contributes to social inequalities in health and health-related behaviors. Bourdieu

argued that high-status groups develop exclusive lifestyles that symbolize their status and are used for distinction and exclusion: i.e., ‘cultural capital’ or ‘affinity with elite culture’. Cultural capital accumulation is assumed to occur via life-long socialization, in which preferences and behaviors are transmitted from parents to children, and formed in formal institutions like education. In addition, Bourdieu suggested that such socialization causes tastes and attitudes to be converted into long-lasting dispositions that are internalized within the so-called “habitus”. These dispositions become, at least partly, ‘hard wired’ in cognitive structures and subsequently constrain and guide behavior in an ‘habitual’ manner – which Bourdieu characterized as “class unconsciousness”. Consequently, cultural capital comprises both a declarative (i.e., deliberate/conscious) and a non-declarative (i.e., automatic/unconscious) aspect – corresponding to dual-process theories. And it is the latter aspect that is often considered crucial in everyday health-related choices.

Yet, extant quantitative research investigating the relationship between cultural capital and health-related variables has thus far only been able to investigate the declarative aspect of cultural capital, since we lack methods to directly measure its non-declarative elements. Indeed, previous studies primarily use survey items that measure respondents’ self-reported consumption and/or appreciation of highbrow cultural practices (i.e., declarative cultural capital), while often interpreting their association with health-related variables as evidence of the role of internalized dispositions (i.e., non-declarative cultural capital). Consequently, scholars to date have been unable to empirically capture the importance of non-declarative cultural capital for understanding (social inequalities in) health-related practices. The current study aims to overcome this limitation by implementing a novel methodology to measure non-declarative cultural capital empirically and exploring to what extent it 1) associates with food-related practices and 2) mediates the relationship between (parental) socioeconomic position and food-related practices.

Methodology

This study draws upon a recently developed analytical tool that uses Implicit Association Tests (IATs) to empirically measure non-declarative cultural capital: one IAT measuring the appreciation of elite over common cultural expressions, and one IAT measuring self-identification with elite over common cultural expressions. These two cultural capital IATs include a wide range of elitist and common cultural expressions, including attributes that mirror conventional measures used to measure declarative cultural capital (e.g., art museum, classical music). Since the crucial element of non-declarative cultural capital is its unconscious deployment of it, capturing it empirically requires that respondents report it in ways that ensure they do not have intentional control over their answers. IATs have been developed for exactly this purpose, and have been successfully applied to identify people’s implicit associations with the attributes of different stratification axes (e.g., gender and race). We embedded the two cultural capital IATs within a larger survey fielded among members of a high-quality panel drawn randomly from the official Dutch population register ($n = 2,436$). In this survey, we also collected data on, among others, various socioeconomic status indicators, conventional measures of declarative cultural capital, and a short food frequency questionnaire on the consumption of fruits, vegetables, whole grain bread, fried snacks, chips and salted nuts, and sugar-sweetened beverages. In the current study, we will use 1) generalized linear regression models to assess the relationship between declarative and non-declarative cultural capital on the one hand and the consumption of the food products listed above on the other, and 2) mediation analysis to assess to what extent the relationship between (parental) socioeconomic position and food consumption is mediated by declarative and non-declarative cultural capital.

Results

Respondents were able to sort the IAT-attributes as common or elitist in a consistent and fairly easy manner, which indicates the IATs ability to capture a valid measurement of non-declarative cultural capital. As expected, the IAT-scores also correlated with conventional measures of declarative cultural capital and the educational and income levels of both the respondents and their parents. Results pertaining to the relationship of declarative and non-declarative cultural capital with the food-related practices will be available in spring 2024.

Conclusion

The unconscious deployment of cultural capital plays a key role in Bourdieu-inspired interpretations of the

widespread observed relationship between indicators of socioeconomic status and health-related outcomes. Nonetheless, such interpretations remain mostly hypothetical because an empirical measurement of non-declarative cultural capital is lacking. Our study aims to overcome this limitation by implementing a tool that measures non-declarative cultural capital empirically, and exploring to what extent it is associated with (social inequalities in) food-related practices.

We are what we eat? Culinary narratives and cultural capital in social space: A qualitative analysis

Stephanie Beyer (Leibniz University)

In recent years, a number of studies have examined the distribution of different forms of capital and lifestyles in social spaces, including food preferences, providing good insights into different national spaces. For example, Trübner et al. (2022) reconstruct the German space of sustainable food consumption, Atkinson (2021) focuses on the contemporary British 'food space', Burnett and Veenstra (2017) also include food practices in their analysis of the Canadian social space, and Flemmen et al. (2018) study cultural distinctions and social class divisions of culinary tastes in Norway. In each of these spaces, we find a homology between the amount of cultural capital and culinary practices, such as food preferences, the types of restaurants people favor, and the size of their meals.

To complement this important stream of literature, which is primarily concerned with *structural* differences in food-related practices, I focus on *how* food practices and culinary tastes are justified and enacted at different positions in social space, and how these differences are negotiated by the actors themselves. Therefore, this paper uses a qualitative approach to analyze people's reported food-related practices, particularly in relation to the relevance of cultural capital and its interdependence with economic capital. My analysis is based on interviews with 24 participants conducted in a large German city, covering a wide range of social positions and ages, with the youngest participant being 24 and the oldest 66 years old.

In the interview, the participants talked in detail about their perceptions of a healthy lifestyle, their dietary habits, where they buy their food, the importance they ascribe to the origin and ingredients of products, as well as changes in their eating habits and the reasons for them. In addition, all interviewees completed a short questionnaire after the interview, in which they indicated how often they consume different products such as vegetables, fruit, meat, fast food, soft drinks, alcohol, sweets, or nicotine. Moreover, indicators of economic capital, such as income and wealth, as well as the different forms of cultural capital (embodied, objectified, institutionalized) were also included in the questionnaire.

In order to reconstruct different narratives of food-related practices, the interviews are analyzed using qualitative content analysis, distinguishing between those with high and those with relatively low amount of cultural capital.

Health Lifestyles and Feeding Practices as Cultural Capital

Stefanie Mollborn (Stockholm University)

Introduction

Within sociology, much recent empirical and theoretical work around health and inequality has emphasized health lifestyles, defined by Cockerham (2005:55) as "collective patterns of health-related behavior based on choices from options available to people according to their life chances." Alongside other forms of capital (Bourdieu 1986a), cultural capital strongly informs people's health lifestyles—an important facet of which is diet-related behaviors. More recently, a growing body of research (e.g., Eriksen et al. 2023, Korp 2008; see Mollborn, Lawrence, and Saint Onge for an overview) has emphasized the *other* causal direction: Health behaviors and health lifestyles are becoming an increasingly powerful form of cultural capital that serves to perpetuate

inequalities across lives and generations. This study examines how this happens from the lens of behaviors and narratives around food and body size.

Methodology

Two large qualitative data sources are analyzed (see Mollborn, Pace, Rigles 2021, and Mollborn & Modile 2022, respectively). The first is a longitudinal study of families in two middle- to upper-middle-class communities in the western US. The first round of data collection included home-based observations of 30 families with 9- to 11-year-old children paired with parent interviews, another 21 standalone parent interviews, 6 focus groups with community parents, and 9 key informant interviews with people who worked with children in the communities. Three follow-up waves, including two during the COVID-19 pandemic, followed parents and now-teenage children for 5 years, with at least 20 interviews at each wave. The second data source is a complementary set of over 100 interviews with young adults aged 18-25, many of whom came from these or similar communities. The sample includes considerable variation by both family and community class background.

Results

Building on our earlier analysis that articulated health lifestyles as a form of cultural capital using the family-based qualitative data (Mollborn, Rigles, and Pace 2021), this study focuses on how parents' feeding of their children has become an influential form of cultural capital in these communities. More than any other behavioral aspect of children's health lifestyles, children's eating is controlled by parents and schools to create public performances of "health" that showcase children's internalization of norms encouraging intake of low-calorie foods and eschewing consumption of high-calorie and processed foods. These behaviors produce a socially classed thin body that is a very high priority for parents in these communities. Girls are subjected to these pressures more explicitly than boys, though both internalize these food-related norms and display the embodied cultural capital it produces. Five years later as teenagers, these young people evidence considerable anxiety around food and body size but also display internalized cultural capital as a result of their earlier experiences.

Analysis based on the interviews with young adults shows how they do narrative work to further bolster—beyond the behavioral displays and embodiment that they also evidence—the cultural capital created by childhood feeding practices. Class-advantaged interviewees use talk about less advantaged people's eating and body sizes as a foil to showcase their own hard work, moral worth, and discipline as evidenced by their understandings of correct eating. This is true even in the many cases in which the young adult is not currently eating nutritiously. In contrast, class-disadvantaged young adults focus very little on food and body size, instead framing health around hygiene, lack of illness, and/or social and financial well-being. This lack of narrative around eating translates into cultural resistance and powerlessness when many of these class-disadvantaged interviewees attempt upward class mobility, demonstrating that the cultural capital generated by food-related behaviors, narratives, and resulting embodiment has real consequences for people's lives.

Conclusion

This study is limited by a lack of generalizability due to its sampling strategies arising from its goal of producing in-depth qualitative data, as well as by the absence of data on families from class-disadvantaged communities. Despite these limitations, pairing these data sources permits a look at how class-advantaged young people are socialized into health lifestyles and receive cultural capital from understandings of food and eating, as well as how they use these resources in young adulthood in ways that perpetuate inequalities in the long term. The findings suggest that scholars of cultural capital should seriously consider the extent to which classed understandings of "health" and bodies are a very powerful aspect of contemporary cultural capital, in part replacing earlier understandings of cultural capital based on consumption and knowledge of "high" culture.

Embodied cultural capital and health inequality: Evidence from China

Xueqing Zhang (The University of British Columbia), Gerry Veenstra (The University of British Columbia)

Background

Strong associations between socioeconomic resources and health-related factors have been well documented (Adler and Newman 2002; Link and Phelan 1995). In recent years, some scholars have utilized Bourdieu's capital theory to operationalize socioeconomic resources (Braveman and Barclay 2009; Veenstra and Abel 2015; Zhang and Veenstra 2022). Bourdieu (1985) used the term 'capital' to refer to resources for individual activities that are socially valued and objects of struggle. He nominated three centrally important forms of capital in social life: economic capital, cultural capital, and social capital. Bourdieu (1985) conceptualized cultural capital as a person's education (knowledge and intellectual skills) that provides an advantage in achieving a higher social status in society. He identified three types of cultural capital: embodied, objectified, and institutionalized cultural capital (Bourdieu 1986). Embodied cultural capital refers to knowledge or skills that individuals gain through their habitus, which includes both consciously acquired and passively inherited aspects of oneself, typically obtained from family through cultural socialization (Bourdieu 1986). Objectified capital refers to the possession of objects of culture, such as books and artworks. Institutionalized capital refers to being recognized by elite institution, such as a university degree (Bourdieu 1986). Several studies have established a connection between health and cultural capital. For example, Khawaja and Mowafi (2006) found that cultural capital strongly and significantly predicted the self-rated general and mental health of women residing in impoverished urban settings. Veenstra (2007) applied Bourdieu's cultural-structuralist approach to depict and conceive social classes in social space, including factors assessing various cultural tastes and dispositions, to identify class-related health consequences in a Canadian province. Researchers from Sweden found that attending cultural events corresponds to a lower risk of mortality (Bygren, Konlaan, and Johansson 1996). In China, researchers studying socioeconomic resources and health inequality in China have also incorporated cultural capital as an important factor facilitating individuals' health. For instance, Zhang et al. (2009) determined that education is associated with women's healthcare-seeking behaviors while Zhang and Veenstra (2022) found that parental education was associated with the self-rated health of women, an association that was fully explained by women's adulthood educational attainment and income.

Objectives

Previous studies indicate that cultural capital has a significant influence on health, both in Western societies and in China. Nevertheless, we contend that there are two major problems and limitations present in the existing research on this subject. First, the majority of previous research characterizes cultural capital by measuring educational attainment, namely, institutionalized cultural capital. However, there has been limited focus on embodied cultural capital, especially for health inequality research in the Chinese context. Indeed, due to its complex nature, it is hard for scholars to directly measure embodied cultural capital using one or two factors such as educational achievement and possession of cultural items. Still, a small amount of research has given attention to the role of embodied cultural capital. For example, Khawaja and Mowafi (2006) utilized participation in cultural activities (such as reading books, volunteering for cultural events) as a means to assess embodied cultural capital. They discovered a significant association between this measure and self-rated health among low-income Lebanese women living in poor urban communities. Another study in Sweden created an index for embodied cultural capital from seven independent variables: attending the cinema, the theatre, a concert, museum, art exhibition, church service, and sports event as a spectator (Konlaan, Bygren, and Johansson 2000). One of the primary objectives of this study is to develop an index for embodied cultural capital specifically tailored to the Chinese context.

The second problem is the lack of attention on capital interplays. It is important to note that Bourdieu's theory of capital does not solely focus on each individual form of capital in isolation. Instead, the theory emphasizes the complex interplay between the three categories of capital and how it contributes to the perpetuation of social inequalities and the allocation of power (Abel and Frohlich 2012; Bourdieu 1985; Swartz 1997). Participation in cultural events can be considered as an indicator of individual's embodied cultural capital acquired through habitus. However, this behavior may be closely tied to individuals' financial and social resources (Abel 2008). Thus, it is important to explore connections between embodied cultural capital, economic capital and social capital in order to grasp the actual significance of cultural capital for health and wellbeing.

In light of the above, we pursue the following research questions utilizing a nationally representative survey dataset of Chinese adults: 1) Does embodied cultural capital have an effect on BMI, self-rated health and self-rated mental health above and beyond institutionalized cultural capital and economic capital? 2) If yes, is the effect of cultural capital on health conditioned by institutionalized cultural capital and/or economic capital?

Methodological Challenges in Medical Sociology Research, Regular session – Chair: Christof Wolf – Room K.103

Normative sociology is inevitable

Georgi Sarov (Trakia University)

Introduction

Social theory and modern science, in general, strongly advise against the use of normative constructs, although medicine accepts disease as abnormality, psychology seeks normalizing human psyche and sociology criticizes social vices and recommends social control. Norms resemble myths – unreal and existing simultaneously. Marx's unsuccessful attempt to create normative sociology likely contributed to this situation, but the definition of norm is also problematic in medicine and psychology. It appears that modern science acknowledges the need for a solution to the normative problem but has not yet found one.

Methodology

A method of theoretical investigation, grounded in the basic presumption that all sustainably existing things are normal, was employed through content analysis of medical and social theories. By applying this concept to social life, which is understood here as the cohabitation of a group of human creatures, I identify four types of "social subjects" to categorize the four types of social life: personality, community, social systems, and society (Sarov, 2022). Each of these social subjects exists sustainably under specific conditions and engages in interactions with others in precisely defined ways, following natural social norms. The laws of natural normality, characterized by their abstract and universal nature, permit normative interpretation across virtually all spheres of social life.

Results

The motivation of every individual is driven by needs, and these needs arise in response to a perceived loss of normality. Therefore, the state of satisfaction should be acknowledged as a subjective norm, with sovereignty emerging as the guiding principle.

When individuals communicate their subjective concepts, a consensus about norms is formed, and solidarity emerges as the primary principle of normality within a community. Individuals can choose between solidarity and sovereignty if these principles contradict each other. Alternatively, they may find satisfaction in having both, especially when their needs are met by the solidarity of others.

When individuals engage in a collective activity with a shared goal, their behavior is rigorously governed by technical and social rules that position everyone in a role that aligns with their competence and desires. At this level, the supreme principle guiding behavior is justice. Organization is normal when: participants are satisfied with receiving rights in proportion to merits; collectives find that equal contributions lead to equal rewards; and everyone operates in a necessary way. Then sovereignty, solidarity, and justice do not contradict each other.

Each of the three normative criteria mentioned above, when applied independently, has the potential to contradict the others, becoming a source of abnormality. Consequently: Under the banner of sovereignty, egoism can undermine solidarity and justice; conformism may transform solidarity into obedience, suppressing both sovereignty and justice; formalism can corrupt justice, neglecting sovereignty and solidarity. To prevent conflicts,

societies establish legitimate and legal rules that claim to represent the truth about social life but are historically limited and require periodic revisions.

Civilization represents the social life of society. The guiding principle of civilizational existence and growth is improvement in accordance with the truth. This imperative necessitates unequivocal definitions of right and wrong, good and evil, freedom and limits. The resolution of disputes, driven by truth or power, shapes the trajectory of progress or conflict within society, respectively. The inherent contradiction between truth and power becomes a defining factor in societal development.

Conclusion

Behavior is a response to normative deviations, driven by an innate desire for normalization. Decisions are formulated basically on four normative principles, defined subjectively, collectively, rationally, or from a perspective social laws and cultural beliefs. In practical terms, normative principles often face falsification, leading to the emergence of social conflicts. These conflicts, in turn, serve as symptoms of social pathology, with repercussions for personal health and life. So, normative sociology serves not only as a fresh perspective within social theory but, more significantly, as a foundation for establishing robust and coherent health sociology. The principles and frameworks elucidated by normative sociology provide the necessary groundwork for understanding, diagnosing, and addressing social issues that have a direct impact on human health. This interconnectedness underscores the importance of normative sociology in shaping a comprehensive understanding of the intricate relationship between societal norms and individual well-being.

Normative sociology, as a novel perspective in social theory, stands as a crucial foundation for robust and coherent health sociology. The core focus of normative sociology lies in establishing an unequivocal definition of norms, analyzing their violations, and proposing measures to restore normalcy in social life. As a scientific discipline, normative sociology should maintain openness to ongoing refinement and updates of normative definitions, guarding against ideological exploitation.

Health sociology, in this context, can be viewed as a specialized branch of normative sociology. It applies normative definitions to diagnose and treat social vices that negatively impact human health. It is important to distinguish normative sociology from ideological paradigms and political deviations, which often result from falsification and the exertion of power.

Social life: A new candidate for the subject of sociology

Georgi Sarov (Trakia University)

Introduction

The landscape of social theory is characterized by four prominent theories, each offering a unique perspective on the subject and employing distinct methodologies. Durkheim emphasizes social facts and statistical investigation, Weber categorizes social actions into ideal types, Parsons views social life as an evolutionary product with a defined institutional structure, and Marks believes that social life has normative base and conflict reality and offers social changes toward more equitable relationships. Merton, recognizing the limitations of grand theories, advocates for more realistic goals within middle-range theories. While modern sociology aligns with Merton's approach, the question arises: Can sociology be considered a classical science without a coherent theoretical framework? This paper explores the potential consolidation of fundamental ideas in sociology through a revision of its subject and methods.

Method

Following the scientific tradition, three methods of thinking—traduction, induction, and deduction—are well recognized. Another method used but not well defined is coordinate thinking that helps for the orientation of the parts role in the whole. If one wishes to label it within the scientific tradition, an appropriate term might be

conduction. Conduction enables the revision of separate viewpoints by comprehending their validity and limitations, combining them with other perspectives to construct a complete and congruent picture. The primary deficiency in paradigmatic thinking lies in overgeneralization, marked by an excess of induction and insufficient conduction.

Results

Grand theories, despite their shortcomings, have valid elements, but are wrongly generalized. Their partial validity necessitates a more inclusive perspective. While grand theories indeed possess true cores, they are often wrongly generalized. Nevertheless, these theories remain applicable in some aspects of real social life. The underlying problem is evident – when discussing society from specific perspectives, grand theories tend to overlook their statements from alternative viewpoints and, instead, stand in opposition. This lack of a comprehensive approach may raise reasonable objections. Considering that all grand theories analyze social life from different perspectives, one can readily conclude that the subject of sociology should encompass social life itself. However, this assertion prompts a critical question: Who lives social life, and how many social lives exist? Through my theoretical analyzes, I arrive at the conclusion that social life is experienced by four types of social subjects: 1) individuals who integrate their minds into the collective consciousness of social subjects at a higher level; 2) a group of persons forming a shared consciousness through mutual understanding (community); 3) collectively working individuals with shared goals (social system, organization); and 4) a group of persons with shared beliefs and rules (society). Social subjects primarily function as normative creatures, grounded in various forms of shared consciousness. Obeying the norms, they not only survive but also thrive and develop. The social life of different social subjects are ruled by different natural laws. However, when individual personalities integrate into a community, when communities organize for cooperative actions, and when organizations are governed by societal rules, social life attains consistency, signifying normalcy. With these presumptions in mind, one can systematically construct sociology as a cohesive theory using existing components: Durkheim is correct in asserting that social life produces measurable social facts, making him a progenitor of descriptive sociology. Weber's insight that social life is experienced through social actions, presented as ideal constructs, positions him as a pioneer of analytical sociology. Parsons rightly emphasizes that the existence of social functions necessitates the presence of social structures, earning him the title of a founding figure in institutional sociology. Marx's recognition of the natural normative aspects within social life, influencing the development of civilization and giving rise to social conflicts, designates him as a key figure in normative sociology, despite its ideological form.

Conclusion

Social life emerges as a credible candidate for the subject of sociology. By integrating the insights of Durkheim, Weber, Parsons, and Marx, a coherent theoretical construct can be formed. Durkheim's emphasis on measurable social facts aligns with descriptive sociology, Weber's focus on ideal social actions contributes to analytical sociology, Parsons' recognition of social functions and structures informs institutional sociology, and Marx's acknowledgment of normative aspects guides normative sociology. In this context, health sociology is involved with all social subjects, as each of them incorporates individual health needs and social issues. The accurate application of general social theory is crucial for the practical implementation of health and medical sociology.

Measuring of online social capital in health studies: A scoping review

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Introduction

Social capital refers to a resource possessed by an individual or by a group or society and could be defined as the good that is available to both individuals and communities through members of social networks and social

participation. Depending on the theoretical approach as an indicator of social capital there are distinguished generalized trust, membership of voluntary group, civic engagement, social participation, social integration, social network, social support. In health studies the most widely used is the concept of social capital developed by Putnam. Considering aging of the population and other observed macrostructural changes as well as the outbreak of the Covid-19 pandemic, there is increasing interest in the role of social capital in relation to health and quality of life of middle aged and older people. Especially, the role of massive development of modern communication and information technologies in the context of the social capital seems to be important. Thus, there is increasing interest in possibility to use information and communication technologies (ICTs) to maintain or build social capital. Social capital gathered via connecting to others using ICTs is defined as online social capital. For the future research projects it is important to verify existing measurement tools of online social capital and their comparison in terms of assessed aspects of social capital as well as psychometric properties.

Objective

Thus, the aim of the study is review of research tools enabling assessment of social capital indicators considering the aspect of using modern technologies (online social capital), which can be used in health studies.

Methods

Theoretical or empirical studies concerning development or validation of the questionnaire methods to assess online social capital were considered. The studies conducted in the adult population from any country and sociocultural setting focused on health or directed to general population were checked. An initial limited search of Medline and ProQuest was undertaken to identify optimal strategies of querying bibliographic databases. Formal query was carried out in the following databases: Medline (via Ovid), Embase, Web of Science, ProQuest, CINAHL covering 1 January 2000 to 24 August 2023. Following a pilot test and calibration exercise, titles and abstracts were screened by two reviewers independently for assessment against the inclusion criteria for the review using Covidence online tool. Potentially relevant sources were retrieved in full and uploaded to Covidence. The full text of selected citations were assessed in detail against the inclusion criteria also by two reviewers independently. In case of disagreements at any stage of the selection process they were resolved by the third reviewer not involved in the screening and discussed in the core team if needed.

Results

7040 studies were screened among which 81 were classified as primary reference studies. The preliminary results showed that there are only a few scales which differentiate online and offline social capital. Most of scales used to measure online social capital are adaptation of the scales existing previously to measure social capital as a whole (offline). There is lack of scales directed typically to the older populations.

This research was funded in whole by National Science Centre, Poland [2022/45/B/NZ7/04030]

Relationships between different aspects of health: A systematic review

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Introduction

Health, a multidimensional construct, manifests itself through various aspects and measurements such as morbidity, functional limitation, subjective evaluation of health, and mortality. These elements are often assessed individually, without comprehensive exploration of their interconnections. Even more rare are studies where the relationships between the different aspects are included in one model. This systematic review seeks to elucidate and synthesize studies that examine the intricate relationships between morbidity, functional limitation, subjective health, and mortality.

Methodology

The review relies on an exhaustive systematic review methodology using the Scopus database, with the aim of

identifying scientific articles that employ statistical models that encompass the simultaneous investigation of at least **three** health dimensions: morbidity, functional limitation, subjective health, and mortality. The initial search identified 6,754 such articles and, through meticulous screenings, 81 articles were ultimately selected for detailed analysis. We then analyzed them according to the relationships and interconnections between the different aspects of health.

Results

When it comes to the descriptive characteristics of the article data set, the pool of articles is quite diverse. The earliest selected article was published in 1982, the latest in 2017. Most (64%) of the articles have been published after 2005. In the 81 selected articles, materials from 96 locations in 33 countries were analyzed. Most of the studies were from North America and Europe, but there were also studies from several Asian countries (China, Japan, Thailand, Taiwan, Sri Lanka, Singapore, and Indonesia) and Australia. The least studied continent is Africa, with only two studies. A large majority (84%) of the articles analyzed men and women together. When it comes to the methods used in the analysis, the majority (59%) of the articles analyzed longitudinal data, while 40 percent used cross-sectional data.

Exploring the interrelationships between the health aspects revealed some expected and some surprising findings. The diverse landscape of relationships between health dimensions becomes the primary outcome of this systematic review. In particular, morbidity was rarely incorporated as an outcome in the models under examination. The analysis showed significant variance in the model structures, demonstrating the complexity inherent in understanding the interaction between health dimensions.

Contrary to expectations, the analysis suggested that no singular aspect of health consistently predicted other dimensions. Notably, the most robust association emerged between morbidity and subjective health, observed in 70 percent of the analyzes investigating this relationship. However, subjective health predicted mortality in only 52 percent of articles that analyzed this relationship.

A crucial revelation was the dependence of results on the metrics used to assess health dimensions. Combined measures of morbidity and functional limitation emerged as superior predictors compared to individual indicators. Despite inherent limitations, **subjective health** emerged as a somewhat effective, albeit far from perfect, predictor of short-term **mortality**.

Conclusions

This systematic review sheds light on the intricacies of health interrelationships, unraveling patterns, and nuances in the existing body of research. The scarcity of models that incorporate morbidity as an outcome underscores a research gap that warrants further exploration. The inconsistency in predictive power among different health dimensions emphasizes the complexity of health dynamics and the need for nuanced considerations in future studies.

The robust connection between morbidity and subjective health highlights the importance of subjective evaluations in understanding health and morbidity. However, the nuanced relationship between subjective health and mortality warrants a deeper exploration to discern the underlying factors influencing this association and warns researchers not to use subjective health as a 'universal predictor' of mortality.

Moreover, the dependence of results on measurement methodologies signals the importance of introducing standardized approaches in health research. The use of combined measures of morbidity and functional limitation emerges as a promising avenue for more accurate findings.

In conclusion, this systematic review advances our understanding of health as an intricate interplay of dimensions. It invites further inquiry into unexplored facets, encouraging researchers to adopt comprehensive models that embrace the complexity of health dynamics.

The use and misuse of race and ethnicity in health research: Developing guidelines for a race-conscious approach in Europe

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Introduction

Health disparities associated with the socio-politically constructed concepts of race and ethnicity persist in various settings. Racial/ethnic disparities endure in health statuses, outcomes, access to quality healthcare, and determinants of health. The issue gained renewed attention during the COVID-19 pandemic, when global evidence revealed that racially minoritized groups were disproportionately negatively affected by both the disease and the response to it. Health disparities are a key focus of Public Health efforts, yet structural/systemic racism, an important root cause of these disparities, often remains unnamed and unaddressed. The field of Public Health exhibits a general lack of race-consciousness, often manifested as white ignorance or color/race-blindness. This in turn leads to research, policy-making or practices that are race-based or race-evasive, inevitably contributing to the (re)production of health inequities.

Our goal is to address the prevailing lack of race-consciousness, by raising awareness around the role of racism as a structural barrier to health equity. We aim to initiate and sustain a crucial conversation on race in Public Health. Specifically, we will introduce the preliminary guidelines resulting from our systematic search and review on recently published health research articles. These guidelines aim to assist health researchers on how to appropriately utilize and deploy data on/with racially minoritized groups. They provide insights into conducting race-conscious research and effectively using the findings to address systemic racism in health. The session provides a platform for collective reflection and idea exchange on the development and implementation of anti-racist practices in public health research.

Methods

A systematic search and review was conducted to assess health research publications on/with racially minoritized groups in Belgium, France and The Netherlands. These countries were chosen based on the researchers' expertise and language proficiency. The objectives of the review were to understand (1) the terminology used for health research on/with racially minoritized groups, and the operationalization of these terms; (2) the types of data on race, ethnicity and proxies used, along with the reasons behind their utilization; (3) the methodologies employed; (4) the available evidence regarding the use of racially minoritized groups data to promote racial equity in health; and (5) existing best practices in research and data use on/with racially minoritized groups. A total of 590 documents published between January 1st, 2018 and July 8th, 2022, focusing on Belgium, France, The Netherlands and their overseas territories underwent data extraction as part of the review process. To address the research questions, a comprehensive, critical analysis was conducted utilizing both quantitative and qualitative approaches.

Results

Concerns on the quality of health literature arise, with publications exhibiting shortcomings such as problematic terminology and poor conceptualization, a general lack of definitions, absence of references for selected terms, inconsistencies in terminologies and operationalization within the same paper, and insufficient argumentation. Some publications also (re)produce stereotypical views of racially minoritized groups, without evidence-based work to back them up. In general, terminology referring to 'race' and 'racism' is shunned. These issues are troubling not only with regards to the authors but also to the reviewers who assessed and approved these articles for publication. An important implication of this, is that publications that poorly meet scientific standards have little utility in addressing racial health disparities.

Following this examination, we will highlight significant guidelines and tools concerning research design, methods for data collection and recording, data interpretation, and the dissemination of results. For this, we

draw on established guidelines at both national and European levels and best practices from the reviewed documents. We will also introduce a qualitative evaluation of health publications using our categorization system, which includes classifications such as race-blind, race-based, race-evasive, and race-conscious.

Conclusions

The collection of equality data plays a vital role in evaluating the health condition of racially minoritized groups and effectively addressing health disparities and structural inequities. However, it is imperative for researchers to address key questions—specifically, the reasons behind collecting the data (the "why") and the methodology employed in the data collection process (the "how")—before embarking on such endeavors. Lessons learnt from this work will be used to reflect on our role and responsibilities as health researchers.

Migration and Ethnicity in Health, Regular session – Chair: Theoni Stathopoulou – Room K. 201

Facilitators and Barriers of Maternal and Infant Healthcare Access for Undocumented Migrants: A Systematic Review

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Background

Adequate access to healthcare in the first 1000 days of life is concurrent with lifelong well-being and should be guaranteed regardless of nationality, legal status, and social conditions. By exploring how migration status affects the social determinants of health, this review provides a nuanced understanding of the barriers and facilitators encountered by undocumented migrant women and their infants in the first 1000 days of life when accessing healthcare.

Methods

Following the PRISMA guidelines for systematic reviews and the registration of the protocol on PROSPERO (registration number: CRD42022328220), a literature search in PubMed, Embase, CINAHL, PsycInfo, and Scopus from 2000 to 2022 was performed.

Results

Of 1295 initial results, 45 studies met the inclusion criteria. Identified barriers of healthcare access in the first 1000 days include (1) legal barriers, such as the criminalization of migrants or the complexity of administrative procedures, and (2) socio-cultural barriers, such as inadequate health literacy and financial challenges. Additionally, ethical concerns as barriers of healthcare access were also mapped from the included papers. Facilitators that improved healthcare accessibility include (1) legal facilitators, like dedicated healthcare clinics, and (2) socio-cultural facilitators, such as language support and healthier lifestyle habits.

Conclusion

Considering the health consequences on future generations, the economic implications, and the vulnerability of pregnant (migrant) women, these findings offer examples of facilitators that could be put into place to move towards universal health coverage. Achieving this requires a holistic multidisciplinary approach that shifts from exclusion and criminalization to support and compassion.

Self-care among descendants of immigrants with chronic conditions: Intergenerational relationships and power dynamics

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Introduction

In Belgium, approximately one-fifth of the population has foreign origins. According to acculturation theories, descendants of immigrants may have “bicultural identities”, which comprise the culture of their parent’s country of origin and the culture of the host society. The ability to integrate and endorse different cultures differs between individuals. Studies suggest that “strongly” bicultural individuals would make more informed decisions about their health thanks to their more integrated thinking. Making informed decisions is crucial for taking autonomous control over one’s health, especially in the case of chronic conditions where patients make daily decisions about self-care activities. These activities may be advised by health professionals, relatives, or undertaken by patients themselves. This study focuses on descendants of international immigrants living in Belgium. The current literature focuses mainly on the effects of acculturation processes, potential trauma transmitted from refugee parents, and experiences of discrimination affecting their mental health. However, little is known about managing chronic conditions among descendants of immigrants distinctly. The first aim of this inductive research is to understand the mechanisms influencing self-care activities among descendants of immigrants.

Methodology

We used inductive qualitative methods inspired by Grounded Theory. The principles of intersectionality were integrated at different research stages to understand the diversity of power dynamics present in the population. In-depth interviews were conducted in Brussels and Wallonia with descendants of international immigrants living with chronic conditions. Participants were at least 18 and had lived in Belgium since early childhood (max.6 years old). They were recruited from ambulatory health centers, local associations, and the researcher’s network. We used theoretical and snowball sampling, including participants with various characteristics (i.e., ethnic backgrounds, socio-economic status, education level, and gender). At first, we invited them to talk about the global experience of managing their chronic condition. As the topics emerged during the interviews, we then focused on family relationships and experiences of discrimination and oppression. The data collection and analysis were carried out concurrently allowing for the evolution of the questions asked. We used constant comparative analysis enriched with intersectionality to explore how combinations of social categories shape the experience of chronic condition management. Additional data sources were used: observations, interviews with healthcare professionals, and literature, especially on historical context to generate and specify hypotheses.

Results

After conducting four interviews with descendants of immigrants and four interviews with professionals (data collection is still in progress), two main topics emerged: intergenerational relationships between migrant parents and their children, and discrimination and power dynamics within and outside the healthcare system. The self-care practices reported by the participants are shaped by dynamics taking place within the family, in the healthcare system, and in settings such as schools and workplaces.

According to respondents, the way their parents used healthcare services and other care practices during childhood can influence their own care decisions. Respondents can follow similar care patterns or create their own strategies by adapting or rejecting those of their parents. Respondents have also mentioned family expectations of health and administrative support from descendants of immigrants. However, providing such support may limit their availability for self-care. Family support also exists in the opposite direction, and advice from parents for managing the chronic condition may be perceived as supportive or irrelevant. According to the literature, the strong intergenerational solidarity existing in migrant families can be explained by migration experience rather than belonging to collectivist cultures. Some respondents may feel uncomfortable disclosing

some of their self-care practices within their family. This result could be partially explained by the concept of “migration debt” [8], which leads some descendants of immigrants to hide their vulnerabilities from their parents. Among respondents, medical mistrust is a common issue that can take many forms based on social characteristics and personal or vicarious experiences from their parents.

Respondents belonging to ethnic minorities have often faced discrimination outside of healthcare since they are at school, sometimes intertwined with discrimination because of visible disease. Experiences of discrimination, causing stress, were interpreted by some participants as a cause of their disease when its etiology was unclear. Such experiences lead to unique ways of managing the chronic condition, for instance by searching for strategies to hide the disease or relying on practitioners and remedies from the country of origin. According to the literature, discrimination against descendants of immigrants can lead them to avoid seeking healthcare and tends to become more frequent as healthcare needs increase, as is the case with chronic conditions.

Conclusion

Our results contribute to understanding the specific experience of descendants of immigrants living with chronic conditions in a European country with a century-old migration history. Preliminary results indicate that intergenerational relationships shape self-care activities through various mechanisms, moving beyond cultural explanations. Discrimination taking place in contexts such as schools, workplaces, and healthcare since childhood also affects self-care activities among descendants of immigrants.

Journey of vulnerability: Understanding healthcare needs of undocumented migrants

Janeth Tenorio Mucha (University of Geneva)

Introduction

Undocumented migrants are foreign residents without a valid residency permit in a country of destination. Different political, economic, and social factors in the migration journey cause people to live undocumented or being at risk of becoming undocumented.

When undocumented migrants live with noncommunicable diseases (NCDs), they experience multiple healthcare needs that are shaped by the different contexts in which they have migrated, lived, and worked. Understanding the social determinants of meeting these healthcare needs is important because undocumented migrants are particularly vulnerable due to social, economic, or legal circumstances.

Methods

We conducted a scoping review to map the socioeconomic factors at the individual and structural levels along the migration journey - from the country of origin to transit, departure, and integration in the country(ies) of destination - that influence the healthcare needs of undocumented migrants living with NCDs.

The literature reviewed includes Medline, Embase, Web of Science, and Google Scholar between 2000 and 2022. We included scientific articles that described interventions, programs, or policies that address cardiovascular disease, cancer, chronic respiratory disease, and diabetes. The data were structured according to the Commission on Social Determinants of Health framework, differentiated along the migration journey. A new conceptual model emerged from data synthesis.

Results

We included 22 studies out of 953 identified. They reported data from Italy, the United States, Spain, Switzerland, The Netherlands, France, Austria, and Sweden. There is no standard operational definition of undocumented migrants; they include irregular migration, individuals who are neither citizens nor legal residents, and self-reporting.

The new conceptual model emphasizes two categories: structural determinants including sociopolitical context and socioeconomic position, and intermediary determinants including individual and health system-related determinants. These categories are interrelated and may persist or change throughout the migration journey.

The structural determinants do not directly affect the healthcare needs, but rather they affect the availability of resources of the intermediary determinants. The sociopolitical context and socioeconomic position can be the root of differential exposure to health-damaging conditions for undocumented migrants compared to documented migrants or native populations.

The intermediate determinants evolve throughout the migration journey and directly shape the healthcare needs. The individual determinants include material circumstances, biological or psychosocial factors, and health-related behaviors. Individual determinants are highly variable throughout the migration journey and are more influential in the country(ies) of destination. The health system-related determinants matter for access to early diagnosis, periodic follow-up, chronic medication, and prevention of complications.

Health system-related determinants and the sociopolitical context overlap and interact during the transit, departure, and integration in the country(ies) of destination. Finally, there is a feedback effect of the needs generated by living with NCDs on the structural determinants that operate through income, occupation, or policies based on the morbidity or mortality of chronic conditions.

Conclusion

The elements that shape healthcare needs for NCDs in undocumented migrants are complex. Migrant health policies should aim to better respond to the NCD-related healthcare needs of undocumented migrants throughout the disease course and their migration journey, considering social, economic, and legal factors that underlie their health vulnerability.

Legal consciousness and equality: Provider responses to patient requests based on ethnicity, gender, and religion

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The healthcare sector faces challenges with ethnic and religious diversity, with discrimination being widely prevalent. The unique considerations associated with groups having a migration background, encompassing distinct languages, cultural norms, and religious traditions influence their healthcare preferences and choice of providers (Ehman, 2007; Blythe & Curlin, 2019, 487). The term "concordant care" aptly describes situations where caregivers and patients share certain personal characteristics, spanning religious, ethnic, racial, linguistic, gender, or sexual orientation concordance (Cooper et al. 2003; Greenwood et al. 2018; Blythe & Curlin, 2019). Numerous studies underscore the positive impact of racial concordance between healthcare providers and patients on care quality, manifesting in improved communication, extended doctor's visits, and heightened patient satisfaction (Cooper et al., 2003, 907; Chen et al., 2005; Hasnain et al., 2011, 80; Paul-Emile, 2012, 496; Blythe & Curlin, 2019, 489). Recognizing the patient's crucial right to freely choose a healthcare provider is paramount, as trust and collaboration form the bedrock of healthcare. However, instances may arise where this right seemingly clashes with the healthcare provider's right to equal treatment. For instance, when a patient refuses treatment from a healthcare provider based on racial biases (Wheeler et al., 2019; Hennein et al. 2022; Filut et al. 2020). In 2009, Belgium's Constitutional Court issued a pivotal ruling that these types of requests are legally acceptable under non-discrimination law (GwH, 2009, 291.). However, this ruling can, and in my view should, be severely criticized. Besides this, a lack of sufficient institutional support is noted throughout different studies, simultaneously making evident a pressing need for the establishment of reporting systems and supportive frameworks within hospitals (Wheeler et al., 2019; Filut et al. 2020; Hennein et al., 2022).

My research examines how healthcare providers navigate within the Belgian legal framework, how they interpret and explain (potentially) discriminatory requests. We will collect qualitative data through in-depth interviews with 20 nurses in the greater Antwerp region within Belgium during the spring of 2024. The data will be analyzed using thematic analysis. This will enable us to critically examine the current legal framework through the perspective of the healthcare providers. We aim to explore how nurses approach patient requests related to ethnicity, gender, sex, or religion, considering distinctions between request types, patient motivations, and contextual factors. Relevant factors in this regard may be sensitive care contexts such as gynecology or maternal care or the particularly vulnerable identity of the patient or caregiver. (Williams & Mullan, 2017; Bloomberg et al., 2020; Chen et al., 2005, 138). The study also investigates whether responses vary based on the underlying motivations of the patients behind the requests, such as reasons of bigotry versus a need for culturally competent care (Blythe & Curlin, 2019, 488; Garrañ & Rasmussen, 2019, 499). Additionally, it explores nurses' perspectives on existing policies, or the lack thereof, addressing patient requests for a different healthcare provider based on specified criteria.

The research seeks to shed light on how healthcare providers interpret and navigate institutional guidelines and protocols related to patient demands, contributing insights to policy discussions. Furthermore, it delves into healthcare providers' viewpoints on the perceived non-applicability of Belgian non-discrimination laws to patient requests for a different healthcare provider based on specified criteria. By understanding how legal consciousness shapes healthcare professionals' responses to discrimination-related challenges, this research aims to inform policies and promote more effective and equitable healthcare practices.

For this study a sample will be drawn of 20 nurses that will be selected for diversity in terms of ethnic-cultural background, religious background, gender, and age. Preferably the respondents will be professionally active in diverse departments in different health institutions in the province of Antwerp.

Health Policy and Systems, Regular Session – Chair: Patrícia Hilário – Room K.202

A novel model to address vaccine hesitancy in Europe: insights from the VAX-TRUST Project

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Introduction

Vaccine hesitancy is a widespread phenomenon and a considerable challenge to public health. This phenomenon is context specific and a burning issue to healthcare professionals, organizations, and authorities. Therefore, recommendations to address this phenomenon are key to be developed at the country and European level. Within the framework of the VAX-TRUST project, research was carried out in seven countries (i.e., Belgium, Czech Republic, Finland, Italy, United Kingdom, Poland, and Portugal) to formulate recommendations on vaccine hesitancy.

Methodology

A Delphi survey was carried out to a panel of 112 experts and stakeholders of each country of the VAX-TRUST project. The Delphi survey was developed in two rounds and participants were asked to rate their level of agreement in relation to each of the 21 recommendations initially presented. These initial recommendations drawn from the findings of the VAX-TRUST project. An agreement threshold of 85% was applied. Descriptive and inferential statistics were developed to analyze the data.

Results

Sixteen recommendations reached the predetermined level of consensus which consubstantiated six main dimensions of possible strategies to address vaccine hesitancy in Europe. These dimensions, meticulously identified, are as follows: (a) Awareness: disseminating clear, accurate, and evidence-based information to both

parents and healthcare professionals, with a focus on enhancing understanding of immunization; (b) Support: implementing organizational and institutional mechanisms to facilitate communication between healthcare professionals and migrant populations, fostering a supportive environment for informed decision-making; (c) Training: advocating for the scientific and technical preparation of healthcare professionals to enhance their ability to communicate effectively with vaccine-hesitant parents; (d) Agency: recognizing and adapting vaccination strategies based on the individual needs and characteristics of children; (e) Recognition: acknowledging and respecting parents' perspectives on managing their children's health, encompassing practices such as extended breastfeeding, vegetarian or macrobiotic diets; and (f) Engagement: cultivating collaborative partnerships by integrating the specific physical and emotional needs of both children and parents into clinical decisions, thereby fostering a holistic approach to healthcare. Collectively, these dimensions coalesce to form the ASTARE model, a robust and integrated approach that provides a comprehensive framework for guiding initiatives aimed at mitigating vaccine hesitancy in the diverse landscape of Europe.

Conclusion

The ASTARE model aspires to serve as a reference framework, offering guidance for the formulation of European policies aimed at addressing vaccine hesitancy. Tailored specifically for healthcare professionals, organizations, and authorities, this model embodies a people-centered and comprehensive approach to stress the complex challenges associated with vaccine hesitancy. Its overarching goal is to provide a strategic blueprint that not only acknowledges the multifaceted nature of vaccine hesitancy but also equips stakeholders with effective tools and strategies to navigate this critical healthcare landscape. By focusing on healthcare professionals, organizations, and authorities, the ASTARE model seeks to foster a unified and coordinated effort. It recognizes the pivotal role played by these entities in shaping public perception, disseminating information, and implementing policies. The model is designed to empower healthcare professionals with the necessary skills and resources to engage with vaccine-hesitant individuals effectively. Simultaneously, it encourages organizations to implement supportive mechanisms and facilitates collaboration between authorities and healthcare providers, creating a cohesive ecosystem for addressing vaccine hesitancy. Embracing a people-centered philosophy, the ASTARE model places individuals and communities at the forefront of its approach. It recognizes the diversity of perspectives and concerns that contribute to vaccine hesitancy and emphasizes the importance of tailored strategies. By acknowledging the unique needs of different populations and communities, the model aims to foster inclusivity and cultural sensitivity in policy development and implementation. In essence, the ASTARE model is not merely a theoretical construct but a practical and adaptable tool for shaping policies that resonate with the realities on the ground. By embracing a comprehensive approach that considers the various dimensions of vaccine hesitancy, it aims to pave the way for more effective, informed, and people-centered strategies in the ongoing effort to enhance vaccine acceptance across Europe.

The influence of social policies on wellbeing in later life in Europe: A scoping review

Dilare Ecenur Irbik (Free University of Brussels), Bram Vanhoutte (Free University of Brussels)

Introduction

Quality of life in older people is defined and quantified with several concepts such as healthy ageing, successful ageing, or active ageing, with each framework emphasizing different aspects of what ageing better means (Peel et al., 2004). Most studies related to ageing have focused on specific aspects of aging instead of on the process, often with a clear emphasis on either labor market or health aspects of ageing, often at the cost of inclusivity and diversity (Boudiny & Mortelmans, 2011; Foster & Walker, 2015). When a perspective of positive health and wellbeing is taken to examine ageing well, it is remarkable to note that most people manage relatively well in later life despite health challenges (Bowling & Dieppe, 2005). Unlike traditional models of ageing which focus on the absence of pathology or disease, the study of wellbeing in later life, by combining insights from both successful ageing and positive health research agendas presents a fertile field of study (Cosco et al., 2017; Kok et al., 2017; Netuveli et al., 2008; Ong & Bergeman, 2004). This paper aimed to find the gaps in the existing literature on different social policy domains for older people in the EU-28 by (1) creating a comprehensive map of the social

policies on ageing in Europe by reviewing the existing literature on ageing policies and quality of life, and (2) finding evidence on key policies to support resilience in ageing.

Methodology

This scoping review was reported according to the guidance of the Preferred Reporting Items for Systematic reviews and Meta-analysis extension for Scoping Reviews (PRSIMA-ScR) Checklist (Tricco et al., 2018). PubMed and Scopus databases were used to identify peer-reviewed empirical articles on the effect of policies on wellbeing and quality of life in later life in Europe, published between January 2002 to January 2024. Articles were included if they: were empirical studies in English, about social policies related to ageing, conducted in one or more of the EU Member States. The identified articles were independently assessed by the authors and the decision on the articles to be included was reached by a consensus.

Results

Our search string resulted totally in 2,261 articles (published between January 2002 to January 2024, in English, regardless of document type) in Scopus and in PubMed. As next steps, articles will be screened taking into account the inclusion criteria in depth and analyzed according to the following subdomains of social policy: Social participation (e.g., level of social participation in the EU Member States, internet access and types of digital services used in different age groups, challenges in social participation), Supportive environments (e.g., housing, transportation, financial independence, homelessness, energy poverty), Family (e.g., grandparenting, informal care), Social protection (e.g., social security, poverty), Other (e.g., age, gender equality, ethnicity).

Conclusion

This scoping review is an initial attempt to map available primary evidence on ageing policies that support later life wellbeing in Europe. It underlines the need for more and better-quality empirical research, increased co-operation between researchers, policy makers, and stakeholders, and increased rights and obligations to foster the resilience of older people in later life.

Mediating local needs and global medical categories: Japan's 'developmental disabilities/disorders' as a local administrative term

Sawako Shinomiya (University of Exeter)

Introduction

Western psychiatric concepts are spreading around the world, yet a lot of fields, including disability-related welfare and educational services, remain local in many ways. This research is on one form of the local aspects that reflects the country's own policy tradition but often becomes a source of difficulties in international knowledge exchanges. The case study is the local word 'developmental disorders/disabilities' (Hattatsu Shogai in Japanese). This word is an umbrella term for autism, ADHD, LD (learning difficulties), and other developmental disorders/disabilities and was coined by the Japanese government in the 2000s. Rather than using 'autism' (Jiheisho in Japanese), the term developmental disorders/disabilities is more frequently used to refer to autism-like conditions both in daily life and the government. It is not compatible with any internationally used medical category, and the government recognizes it is a medico-legal or administrative concept. While adopting this word in the official educational and welfare systems in Japan has contributed to enriching support for those with disabilities as I will show, this local word usage has also prevented the connectivity of Japanese disability policy with international discussions that simply use 'autism', 'ADHD', or 'LD'. By investigating why this non-medical, non-international term was created and adopted in Japanese disability policymaking, this research aims to deepen our understanding of the local-global relationship in psychiatry-related areas.

Methodology

I analyzed Japanese documents and conducted interviews with doctors, parent group members, care workers,

and government officials who engaged in the process of making the concept of developmental disorders/disabilities starting around the 2000s.

Results

(1) The term 'developmental disorders/disabilities' was coined to refer to a group of people who were not covered in the existing education and welfare system until the 1990s but were recognized as a 'blind spot of the system' in around 2000. The remarkable difference of this term from similar medical categories is the exclusion of intellectual disabilities, which stirred strong criticisms from intellectual disabilities-related advocacy groups. It was because intellectual disabilities were already addressed in the education and welfare systems. So this term reflected the state of the education and welfare systems at that time in Japan, which had paid almost no attention to people without intellectual disabilities who still needed some support. This word was useful to justify addressing the non-existence of support for them. Additionally, using this word tied advocacy groups of autism, ADHD, LD, and other related disabilities together and helped them make stronger claims.

(2) The reason the word 'autism' was not used but the umbrella term together with ADHD, LD, and other disabilities was preferred can be attributed to the fact that the Ministry of Education, which played a central role in creating the term, was primarily concerned about LD as a school problem. Their interest was opposite to Autism Society Japan, which had long argued for an independent support system solely for those with autism. In contrast to the Ministry of Education, the Ministry of Health and Welfare focused on high-functioning autism as a potential source of juvenile crime and did not pay much attention to the other disabilities. Developmental disorders/disabilities served as a contact zone of the two ministerial systems and contributed to defining a shared topic that the ministries would newly address.

Conclusion

This research contributes to a wide range of literature on the local-global relationship by focusing on the administrative, medico-legal concept that bridges local social service provision and global medical categories, and by illuminating how a local authority interprets and rearranges global medical categories. While diagnostic concepts have become increasingly globalized, it is unsure how a globalized medical concept fits or unfits local needs and existing support systems. While the local encounter with Western medicine has been explored by anthropological studies, there is limited sociological research on another aspect of 'locality', namely nationwide social systems such as welfare and education. This study elucidates how local terminology emerges and how global medical concepts are not sufficient for building up local service provisions.

Conceptualizing sexual harassment in academia: Balancing identity-neutrality with intersectionality

Sofie Avery (University of Antwerp; Ghent University), Sarah Van de Velde (University of Antwerp)

Introduction

Since 2022, testimonies of sexual harassment (SH) at Flemish higher education institutions have garnered significant attention in the Flemish media. As a result, universities face increased societal and legislative pressure to develop adequate policies and procedures regarding SH.

Currently, Flemish university policies either define SH in a very general manner, or do not define it altogether. One of the arguments to support this generality is that it is 'neutral': individuals are free to make sense of their own experiences. Many experiences of SH in academia do not fit the dominant narrative, either because they occur in the so-called 'grey area' or because they do not correlate with rape myths that foreground paradigm cases and ideal survivors (cisgender, white, heterosexual women). (Harris and Linder 2017) Due to the pervasiveness of this single story, the perceived neutrality of policy could however leave survivors whose stories do not fit this dominant narrative without the (institutional) vocabulary necessary to interpret and voice their experiences and, moreover, ensure they are heard. This in turn can prevent minoritized survivors, notably those with intersecting minority identities, from getting the help they need.

As such, an “identity-neutral and power-evasive” approach to policymaking has been criticized for individualizing the problem of SH as well as reproducing notions of the ideal survivor, thus resulting in the erasure of minoritized survivors’ experiences. (Harris and Linder 2017) Several studies point to a higher prevalence of sexual victimization among queer people, trans* people, people with disabilities, and people of color as opposed to those with non-minoritized identities (Gross et al., 2006; Edwards et al., 2015; Voth Schrag 2017; Fedina et al. 2018; Keygnaert et al. 2021; Lipinsky et al. 2022)

An international research review on SH in academia suggests that “The diversification of exposure, relating both to exposure to different types of sexual harassment and sexual violence, and also the exposure of various minority groups, should guide the universities’ work of preventing and handling sexual harassment and providing support to those exposed.” (Bundestam & Lundqvist 2020) With this mixed-methods qualitative study, we aim to examine current university policy on SH with respect to its attention to the diversification of exposure to SH in both senses: exposure to different types of SH and exposure of different minority groups.

To this end, we depart from two related research questions: (1) How do Flemish universities’ policies conceptualize SH and (2) how do the actors that put these policies in practice view these conceptualizations?

Methodology

To answer the first research question, we employ Critical Discourse Analysis to analyze policy regarding SH follow-up and policy-related documents at all five Flemish universities. Since sexual harassment is subsumed under the Belgian Wellbeing Act, all documents related to this Act will be included, as well as all related documents that explicitly reference (sexual) harassment, among which disciplinary procedures and codes of conduct. Furthermore, other documents that reference (sexual) harassment and/or aim to explain the university policy to its audience (e.g. public informational websites on complaint procedures) will also be the object of analysis.

To answer the second question, we take the University of Antwerp as a case study. We will conduct in-depth interviews with actors who are tasked by the institution with the follow-up of cases of sexual harassment (ombudspersons, prevention officers, etc.) Through these interviews, we aim to answer two sub questions:

(2.a.) How do the actors who implement university policy conceptualize SH?

(2.b.) How do the actors who implement university policy give meaning to the existing policy framework?

The interview guide includes a number of questions regarding the current SH policy and how it is implemented in practice. In addition, we will use vignettes describing non-paradigmatic situations of sexual harassment at the university to gain a better understanding of how the participants define sexual harassment and which cases they include and exclude.

Results

Our critical discourse analysis of the five Flemish universities’ SH policy and clarificatory documents yields the following preliminary results 1. There is no policy specifically designed to deal with cases of sexual harassment. Instead, SH is approached from a framework of individual psychosocial wellbeing. 2. SH is characterized in general terms as a personal and subjective matter: behavior that crosses one person’s boundaries may well be acceptable to another. 3. In most policy documents, no mention is made in university policy to these factors of identity as indicators of heightened exposure to SH.

Based on the final results of the policy analysis, the individual interviews will be conducted in March 2024 and first results will be developed in preparation of the conference.

Medicalization and Demedicalization, Regular session – Chair: Nina Van Eekert – Room K.203

The birth of a patient: (De)medicalization of newborns in different stages of neonatal care

Anastasia Novkuns kaya (European University St. Petersburg), Artemiy Minakov (European University St. Petersburg), Anna Klepikova (European University St. Petersburg)

Introduction

As a concept medicalization often denotes the increasing power of medical institutions in society, whose powers go beyond the treatment and prevention of diseases and cover the functions of social control. Medicalization can be also conceptualized as the redefinition of social phenomena in medical categories and the interpretation of social problems as pathological, i.e. related to the medical field (Conrad 1992). This paper proposes to nuance the understanding of de/medicalization and study it not only as a historical process of increasing control by medical institutions and redefining social phenomena in medical categories, but also as a certain register of communication taking place in a medical context.

This work focuses on the production of statuses in medical interaction; therefore, it considers this interaction in an interactionist perspective and relies on the conceptual model of labels (labeling theory) in the analysis of medicalization. The concept of labeling in its various variants (Becker 1963; Goffman 1961; Rosenhan 1973) is an attempt to explain how society labels a particular behavior as deviant, and how this determines the individual's further trajectory within social institutions. According to the labeling theory, a medical context implies that a diagnosis ascribed to a patient is a sort of an interface, which further mediates and determines the interaction of medical personnel with him or her. Focusing on the interactions of medical professionals with each other and with the patients, including their extended version (parents of a new-born), we conceptualize medicalization as a continuum in which constant switching of communicative registries takes place. More particularly, we analyze how medicalization in multiple organizational contexts is enacted in different ways and how differently it shapes the processes of objectification of a patient vs endowing him or her with agency.

Methodology

The empirical data was collected in the framework of ethnographic study. The main research method was a participant observation, which was conducted by a neonatologist-resuscitator. The observations were carried out from December 2019 to November 2023, and amounted to 33 shifts each for 24 hours, which is reflected in the diary entries. Data collection took place in 4 children's hospitals and 12 maternity hospitals. Additional methods of data collection applied in the study were anthropological observations (n = 7), in-depth interviews (n = 18), focus-groups (n = 6) with health professionals, providing neonatal care on different stages (n = 33), and document analysis.

Conclusion

The object of the research is the medical and social categories (labels) used by health professionals to categorize new-born patients. We analyze these labels as reflecting different organizational contexts, on the one hand, and shaping the patients' trajectories, on the other. The research data allows us to analyze medicalization not just as linear and unambiguous mechanism for the implementation of medical power, but as a flexible and dynamic process that depends on the social settings of a particular interaction – the complication of a patient's condition, organizational environments and the set of actors, participating in the interaction. The results of the analysis show that 'social' labels arise in the highly medicalized environment, even when professionals deal with a patient with limited agency. This mode of interaction partly competes with the biomedical approach, which dominates a deeply medicalized field such as resuscitation and intensive care, and signals situations of a 'demedicalising' relationships.

Medically unexplained symptoms: The medicalization and feminization of medical ignorance

Chiara Moretti (University of Milano Bicocca), Kristin Kay Barker (University of New Mexico USA)

Medically Unexplained Symptoms (MUS) refer to persistent symptoms for which medical investigations fail to reveal a specific pathology or biomarker. MUS are said to affect women more than men (Claréus and Renström 2019). Medicine has proposed various explanations for the feminization of these “contested disorders” including biological sex differences predisposing women to somatise, women’s heightened bodily awareness, and gendered differences in health care seeking behaviors. Such argumentation explains neither the female prevalence in MUS nor the cause of these symptoms. In this contribution, we analyze the medicalization and feminization processes of MUS by focusing on two particular syndromes, i.e. Long COVID (LC) and Fibromyalgia (FMS). We have independently conducted research on LC and FMS as biomedical knowledge and illness experience (Barker 2005, Barker et al. 2022, Moretti 2019, 2022). By joining our sociological and anthropological perspectives we bring together our cross-disciplinary and cross-cultural research into a multi-project analysis. Multimethod research is “when two or more research projects are conducted, each complete in itself, to address research questions and/or hypotheses, a topic, or a program” (Sousa and Mendes 2007). A strength of this method, which combines different projects into a comprehensive whole, is the generation of more empirically robust claims about complex social phenomena than is possible through a single study, research design, method, or data type (Hesse-Biber and Johnson 2015; Sousa and Mendes 2007). Via this multi-project analysis, we trace the unhappy marriage between women and medically unexplained symptoms (MUS). Our specific focus is twofold. First, to illustrate how the medical construction of these two syndromes as knowledge categories, are representations of medical ignorance, doubt and uncertainty vis-a-vis women. Second, to demonstrate the gendered consequences of these knowledge categories for the illness experience of FMS and LC. Indeed if, on the one hand, these diagnostic labels aim to contain forms of women’s suffering that are difficult to explain within the biomedical paradigm, on the other hand they remain “empty” categories by providing neither clear diagnostic processes nor effective therapeutic pathways. Such diagnostic categories thus expose women to the risk of seeing their physical suffering delegitimized by health professionals and society at large.

Exploring mutual care as a de-medicalizing practice of health-caring

Do-Yeon Lee (Seoul National University)

Background

Medicalization, the process by which social or behavioral issues become medical problems requiring medical intervention, has dominated healthcare systems for decades. However, amidst growing concerns about the overreliance on medical solutions and the neglect of holistic approaches to health, there has been a burgeoning interest in de-medicalization. Despite this, scholarly discourse on de-medicalization remains sparse, particularly concerning the role of care in fostering alternative health practices. Care, as a fundamental aspect of human existence, plays a crucial role in maintaining both physical and mental well-being. Yet, traditional healthcare systems often overlook the importance of everyday care practices in promoting health and preventing illness. This study seeks to explore the potential of mutual care, a form of reciprocal support and assistance within communities, as a means to advance de-medicalization efforts.

Objectives

The primary objective of this study is to investigate the potential of mutual care in promoting de-medicalization within South Korean communities. By examining community-based initiatives focused on mutual care, this research aims to shed light on the role of care in fostering alternative approaches to health and well-being.

Methods

This study employs a qualitative approach, utilizing multi-case studies with four cases of community-based initiatives promoting mutual care in various regions of South Korea. Cases were purposively selected based on

their active engagement in promoting mutual care practices within their communities. Data collection methods included document analysis, participatory observation, and semi-structured interviews with initiative leaders, staff members, caregivers, and care recipients. Various documents, such as proposals, reports, and meeting records, were collected to supplement the study. Participatory observation was conducted over a period of one month for each case, allowing researchers to gain insights into the daily dynamics of mutual care practices. Data analysis followed Yin's (2009) pattern-matching analysis, focusing on identifying patterns and themes related to mutual care and de-medicalization.

Results

Across all four cases examined, mutual care practices were found to be pervasive and deeply embedded within the fabric of community life. Participants actively engaged in a variety of services, programs, and activities aimed at fostering reciprocal care relationships. During health-oriented activities, such as group exercise sessions or health education workshops, participants naturally demonstrated care and support for each other's well-being. The presence of supportive social networks influenced participants' health behaviors, leading to positive changes such as increased physical activity, improved dietary habits, and heightened awareness of health issues. Moreover, participants reported significant improvements in their overall health and well-being as a result of their involvement in these initiatives, including reduced feelings of depression, increased feelings of empowerment, and a greater sense of social connectedness. Additionally, participants actively shared health information, knowledge, and skills with one another, contributing to the collective well-being of the community.

Conclusion

The findings of this study highlight the critical role of mutual care in promoting de-medicalization within South Korean communities. By fostering supportive social networks and empowering individuals to take control of their health, mutual care initiatives offer a promising alternative to traditional medical approaches. Moreover, the widespread adoption of mutual care practices has the potential to reduce reliance on formal healthcare services, leading to more sustainable and holistic approaches to health and well-being. However, further research is needed to fully understand the mechanisms through which mutual care contributes to de-medicalization and to identify strategies for integrating these practices into broader healthcare systems. Overall, this study underscores the importance of recognizing and supporting the role of care in promoting health and well-being within communities.

Opioid-related stigmatization in chronic pain management: A focus group study

Justine Vanbavinckhove (Ghent University), Fleur Baert (Ghent University), Melissa Ceuterick (Ghent university), Peter Pype (Ghent University), Liesbet Goubert (Ghent University)

Introduction

The use of **opioid pain medication** in the management of mild to severe cancer and non-cancer pain has long been considered the gold standard. Despite the risks associated with high opioid doses (e.g. opioid use disorder and opioid overdose), the prevalence of long-term opioid consumption in the context of chronic pain has quadrupled in the US since 1999. The prevalence of long-term opioid consumption in **Belgium** is also increasing steadily, resulting in the situation where Belgium has the third highest national prescription rate and the number of patients consuming opioid medication at least once a year increased with 88% between 2006 and 2017.

In the US, a proliferation of guidelines, initiatives, and programs have been implemented to reduce the prescription of high dosed or long-term opioid treatment. In recent years, these policy changes have led to the overall opioid prescription rate in the US levelling off and slightly declining since 2012. However, initial research among both patients and providers shows that the implementation of such policies is not without difficulty. For instance, from a **patient perspective**, studies have found that measures such as opioid tapering or pill monitoring often lead to *reduced treatment adherence*, *avoidance of healthcare* or even *termination of care* on behalf of the patient. Patients often report feeling (1) *inadequately informed*, (2) *insufficiently involved in the decision-making*

process, (3) *misunderstood* and (4) *abandoned by the healthcare system*. A non-intentional, yet clinically important consequence of the implemented policy changes, is that the use of **opioid pain medication** seems to have become **highly stigmatized**, even in strictly monitored clinical settings. Recent studies conducted in Northern America support the notion that opioid-related stigma may impose a significant additional *burden* upon individuals with chronic pain in several ways. However, a consensus conceptualization of opioid-related stigmatization in the context of chronic pain is lacking.

Methodology

Current study aims to explore the **lived experiences** of patients with chronic pain who are prescribed opioid medication. Overall, four **focus groups** with chronic pain patients who are currently using or have been using opioids (> 3 months) are conducted. The first two focus groups have already been conducted in the last months of 2023. The number of participants within each focus group ranges from four to eight patients. During each focus group, participants are asked to discuss and elaborate on their personal (potentially stigmatizing) experiences within their social network and the healthcare system regarding their opioid use. Subsequently, the focus groups are analyzed in a qualitative way through Multiperspectival Interpretative Phenomenological Analysis (IPA). IPA seeks to achieve an idiographic exploration of patients' lived experiences, allowing to construct a descriptive account of how they make sense of their experience and context, through the interpretative process on behalf of the researcher.

Conclusion

Five themes emerge from a preliminary analysis of the data. The first theme '**fear of tolerance**' concludes that there is not necessarily a strong association with fear of becoming addicted to opioids. Patients' fear seems to revolve around becoming tolerant to the medication and, therefore, the medication becoming less effective in allowing them to function despite the pain. From this, a second theme '**medication as a tool to maintain functionality**' emerges. Patients refer to their medication as an essential crutch that allows them to function in daily routines and to engage in valued social and work-related activities. Above that, some patients describe their medication as an essential factor in '*surviving*'. The third theme '**selective disclosure of medication use**' states that people are rather selective in choosing with whom to share their medication use, especially in their informal social networks. This is mainly to avoid reactions from outsiders and to avoid receiving stigmatizing labels. Next, the fourth theme '**the dynamic between chronic pain stigma and opioid stigma**' refers to the finding that distinguishing chronic pain stigma from opioid-related stigma is challenging. Clarifying the boundaries between these types of stigma and to position both in relation to each other, remains an important question. Lastly, the fifth theme includes experiences within the '**patient-provider relationship**'. On one hand, some patients receive a great deal of understanding and recognition from their caregivers who prescribe/distribute opioids. In this narrative, patients are given an active role and have the opportunity to shape their own treatment trajectory, from the point of view that the patient has the deepest understanding of their own body. On the other hand, some patients encounter little understanding, recognition and trust from their caregivers. In these kind of relationships, the patient has little opportunity to tell their story or shape the treatment process, as the caregiver holds the decisive position.

To conclude, it remains crucial to acknowledge stigma as an individual and diverse experience. Our method used in this study, IPA, enables the exploration of the individual experience of opioid-related stigma in the context of chronic pain.

"I think I am in suboptimal health": Subhealth narratives among young Chinese people and their broader implications

Lijiaozi Cheng (University of Sheffield)

Introduction

This paper delves into the concept of 'suboptimal health' (subhealth, 亚健康), a term initially popularized by

Traditional Chinese Medicine (TCM) professionals and widely used in public health discourses in China. Despite criticisms of it being a commercial buzzword, subhealth has emerged as a significant framework for young Chinese individuals to articulate their health experiences, particularly in relation to work and life pressures. This study aims to explore how this abstract concept of health becomes embedded in everyday life and is utilized as a means to voice inequalities. Drawing on illness narratives literature and sociological literature on the sense-making process of health and illness, including sociology of diagnosis, risk, and illness narratives, the paper examines how the discourse of subhealth parallels but also diverges from traditional health discourses. It argues that the concept of subhealth reflects a form of 'biographical suspension', offering a platform for collective critique in a context often dominated by individual responsibility narratives.

Methodology

Employing a multi-sited ethnographic approach, this research involves virtual ethnography on the Chinese social media platform Weibo, coupled with interviews with young Chinese people. This methodology provides a comprehensive view of how subhealth is invoked and employed in everyday life, enabling an understanding of its role in navigating and expressing health-related issues. The multi-sited ethnography allows for a nuanced exploration of the interplay between online discourse and personal narratives, providing a rich tapestry of data on how subhealth is perceived and articulated.

Results

The findings reveal that discussions about subhealth enable young Chinese people to frame private narratives that critique contemporary living and working conditions in China. Subhealth narratives are used to articulate a sense of chronic unease and anxiety about future health, reflecting broader societal challenges and pressures. These narratives serve as a bridge between biomedical and traditional Chinese medicine, highlighting a nuanced understanding of health and illness that is both individually experienced and socially constructed. The concept of subhealth allows for a critique of lifestyles deemed detrimental to health and offers a new perspective on illness narratives, encompassing the sociocultural factors shaping health perceptions.

Conclusion

The exploration of suboptimal health narratives among young Chinese people has significant implications for the broader field of health and medical sociology, particularly in the context of the European Society for Health and Medical Sociology's focus on intersectionality and inclusion. The study highlights the importance of recognizing diverse health narratives, like those of suboptimal health, in developing more inclusive healthcare practices and policies. This aligns with the conference themes, emphasizing the need to understand health experiences through the lens of multiple social identities and societal structures. By drawing parallels between the Chinese context and potential European scenarios, this paper advocates for a broader, more inclusive understanding of health narratives. It invites a reevaluation of how diverse health perceptions, influenced by cultural and social factors, can be integrated into healthcare systems and policies to better serve multicultural populations. This research contributes to the ongoing discourse in medical sociology, underscoring the need for culturally competent, patient-centered approaches in understanding and addressing health and illness in contemporary society.

3 July: 17:10 – 18:10

Meet the Editors – Chair: Hannah Bradby - Room K.001

Under the guidance of workshop chair Hannah Bradby, participants will have the opportunity to ask questions, seek advice, and gain practical tips for navigating the publishing landscape. Whether seeking guidance on manuscript preparation, understanding journal requirements, or exploring avenues for collaboration, this workshop promises to be an enriching and informative experience for aspiring researchers in health sociology.

Editors participating to the workshop

- Terje Eikemo, Chief Editor of *Scandinavian Journal of Public Health*
- Karen Lowton, Editor-in-chief of *Sociology of Health and Illness*
- Hannah Bradby, Specialty Chief Editor of *Frontiers in Sociology* & *Medical Sociology*
- Olaf von dem Knesebeck, Editor-in-chief of *International Journal of Public Health*
- Ellen Annandale, Chair of the Trustees of the Foundation for the Sociology of Health and Illness

Creative Workshop (until 18:30) – Chair: Alice Scavardana and Ana Patricia Hilário – Room K.101

Inequalities in Cognitive Functioning: Intersectional and International Perspectives,
Thematic session – Chair: Damiano Uccheddu – Room K.201

Work-family biographies and later life cognitive disability: What are the mediating mechanisms?

Ariane Bertogg (University of Konstanz), Giulia Tattarini (University of Hamburg), Damiano Uccheddu (UC Louvain)

Background

Research has shown that work-family trajectories experienced throughout mid-adulthood are associated with cognitive health at older ages. Additionally, these linkages seem to be gendered and appear to be contingent on the broader cultural and institutional context in which individuals are embedded. Yet, there is little research explaining *why and how* different trajectories are associated with cognitive health. This study aims to fill this knowledge gap by unpacking the relationship between work-family life courses and late-life cognitive functioning, focusing on three different explanatory mechanisms: material well-being, physical and mental health, and social connectedness. Theoretically, they represent different types of reserves important for later life health. Empirically they have been associated with work-family life courses (as outcomes) and cognitive functioning (as predictors).

Design

The empirical analyses use longitudinal data from the Survey of Health, Ageing and Retirement in Europe (SHARE), including retrospective SHARELIFE information on employment and family histories between ages 15-49. We predict cognitive disability (measured as a dichotomous variable indicating *poor short- and long-term memory* based on two standardized tests) with combined work-family trajectories that we computed with Multichannel Sequence Analysis and attached hierarchical cluster analysis.

To elicit the mediating potential of material resources, social connectedness, and physical and mental health, we use the KHB decomposition method using the following variables: income and wealth (representing material resources), the presence of a partner, the presence and contact with (own) children, and participation in social activities (representing social connectedness), as well as the Euro-D index for depression and the Global Activity Limitation Indicator (GALI) for functional limitations (representing general health).

To allow the mediators to operate differently between genders, we ran separate models for men and women. Our study focuses on four selected country cases, representing three different welfare systems with their specific employment and family policies, namely: Sweden, Netherlands, France, and Italy. All statistical models control

for birth cohort, childhood health and socioeconomic status, country of residence, and duration of panel participation.

Results

Preliminary results suggest that, generally, lifetime employment participation and family roles are associated with better cognitive functioning, but the benefits are gender-specific and differ across the four welfare contexts studied. Whereas for men, the absence of family roles is associated with higher risks of cognitive disability, for women, cognitive risks arise from both the absence of labour market participation and family roles.

Additionally, our findings indicate partial mediation (see Table 1, Appendix), whereby material resources and social connectedness, but not health, emerged as explanatory pathways – working in gender-specific ways, however: For men, both a life course with full-time employment but no family roles (Cluster 3) and having experienced union dissolution after fatherhood (Cluster 6) are associated with higher risk for cognitive deficits. In both cases, a major part of this association is explained by the lack of a partner and (contact with) children in later life (not shown). For women, the cognitive deficits of those women who did not (continuously) participate in the labour market (e.g., being homemakers or unemployed) are mostly explained by the lack of material resources (not shown). Continuously partnered mothers who worked part-time after parenthood (Cluster 7) did not differ in their cognitive risks from mothers working full-time (the reference category).

Discussion

This study highlights the need for a nuanced investigation of the long-term cognitive health implications of work-family trajectories, especially those that deviate from the traditional full-time employment and stable family roles, both becoming increasingly common. Our first findings also underscore the importance of gender-specific analyses and highlight the potential of policy interventions to enhance cognitive functioning in ageing populations through economic and social support. In further developing this study, we will delve deeper into the moderating role of welfare systems, examining how economic and family roles differently influence cognitive health across welfare contexts.

Educational and gender gaps in cognitive impairment-free life expectancy across Europe

Donata Stonkute (Max Planck Institute for Demographic Research), Angelo Lorenti (Max Planck Institute for Demographic Research), Hale Jo Mhairi (University of St. Andrews)

Background

Dementia, the seventh leading global cause of death, affects 14.1 million people in Europe and is projected to increase to 15.9 million by 2040 (WHO, 2021). While not all mild cognitive disorders progress to dementia, they do lead to negative health consequences, such as reduced quality of life, increased physical limitations, and elevated risk of depression (Han et al., 2021; Hussenoeder et al., 2020; Lee et al., 2005). Notably, cognitive impairment not only affects the number of years a person lives with a disability, but also reduces their overall life expectancy, typically by 3 to 5 years (Winblad et al., 2016). Beyond the individual, cognitive impairment has far-reaching effects on families and social networks, with informal care needs straining both economic and emotional aspects (Baumgarten et al., 1992; Morris et al., 2021). This further highlights the need to address and support vulnerable groups in the population.

The intersection of gender and education significantly influences susceptibility to cognitive health decline (Livingston et al., 2017). While women experience a delayed onset of cognitive impairment, they face a longer life expectancy with cognitive problems (Hale et al., 2020; Nielsen et al., 2022). Education also plays an important role, with low education associated with higher cognitive risk and more years of disability, while high education reduces the risk of dementia (Clouston et al., 2020; Hale et al., 2020).

While research has begun to explore the underlying mechanisms between education, gender, and cognitive impairment (Nielsen et al., 2022; Winblad et al., 2016), studies investigating how long individuals live cognitively impaired by gender and education in countries beyond limited Western European are scarce. Our study aims to fill the research gap by estimating Cognitive Impairment-Free Life Expectancy (CIFLE) and Cognitively Impaired Life Expectancy (CILE) across 10 European countries, considering gender and education.

Methods

This study employs data from the Survey of Health, Ageing and Retirement in Europe (SHARE). We analyze seven Western European (2004-2019) and three Central and Eastern European (CEE) (2010-2019) countries. We limited countries according to their mortality data quality, which was established elsewhere (Stonkute et al., 2023).

We employ the approach developed and validated by Crimmins et al. (2011) to define cognitive impairment. This approach relies on four cognitive functioning scores based on questions available in SHARE, which was previously explained in detail in a separate study (Morris et al., 2021). These questions assess performance in immediate and delayed recall, as well as verbal and numeric fluency. We create the overall index by summing the scores obtained from all four questions, with a maximum achievable score of 26. Individuals with scores ranging from 0 to 11 are classified as cognitively impaired, while those scoring between 12 and 26 are categorized as cognitively healthy.

In this study, we create life tables specific to gender and education using a multivariate life table approach, explained in details elsewhere (Stonkute et al., 2023). Subsequently, we employ the Sullivan method (Sullivan, 1971) to estimate CIFLE and CILE.

Results

Figure 1 presents initial estimates of CIFLE by gender and education across studied countries. Women generally enjoy more years without cognitive impairments than men. However, this gender gap varies significantly based on education and country. For instance, in France and Slovenia highly educated women have a 9-year compared to men. In contrast, the CIFLE for Danish women is only 1.2 years higher than for men. Among those with low education, gender gaps are smaller.

Higher education is associated with a longer CIFLE. We find substantial country differences with educational gaps ranging between 8.9 years for men, 9.3 years for women in Sweden, and 16.1 years for men, 22.5 years for women in Slovenia. Educational disparities also vary by gender, with women, except in Austria and Denmark, experiencing more pronounced disparities.

In relative terms, higher education correlates with a greater proportion of disability-free life, but the extent of this advantage varies significantly by country, as can be seen in Figure 2. Italian women with lower levels of education expect to spend only 32.2% of their remaining life in good cognitive health, in sharp contrast to highly educated men who expect to spend over 80%, highlighting substantial inequalities in cognitive health. Additionally, for the least educated individuals, except in Denmark and Sweden, the years of life remaining at age 50 with cognitive impairment exceed those spent cognitively healthy, whereas the opposite holds true for individuals with at least high secondary education.

Life course exposure to poverty and risk of dementia in later life

Lucie Kalousova (Vanderbilt University)

Introduction

Dementia, characterized by a decline in cognitive abilities, affects around 5.8 million Americans, a number projected to rise to nearly 14 million by 2050. It is caused by damage to or loss of nerve cells and their connections

in the brain. Age, health behaviors, and genetic risks play significant roles in the development of dementia. Research shows that nearly half of all dementia cases are preventable.

An emerging line of research has documented that adverse neighborhood conditions, such as neighborhood poverty, experienced in mid and later life can amplify risk. Despite the rapidly accumulating evidence showing that older adults living in disadvantaged neighborhoods are more likely to develop dementia, our understanding of the life course dynamics through which the adverse effects of neighborhood disadvantage on cognitive health unfold is limited. On the one hand, the disparity patterns uncovered might be pointing to the centrality of neighborhood resources to maintaining cognitive health in mid to later life, when vulnerability to cognitive deterioration heightens. This explanatory pathway aligns with the sensitive period framework, which holds that the exposures to adverse experiences or environmental influences are more impactful during some periods than others, for example, periods of greater vulnerability. On the other hand, it is plausible that heightened odds of dementia among older adults living in disadvantaged neighborhoods could be a result of cumulative wear and tear, which becomes manifest later in life. This second pathway, akin to *cognitive weathering*, implies compounding effects of early life exposures. The greater odds of dementia measured among people exposed to neighborhood poverty would thus be due to the cumulative burden that began to accrue at much younger ages. Disentangling the life course dynamics of neighborhood poverty and dementia has both conceptual and policy implications. Understanding the relative contribution of exposure to neighborhood disadvantage at different life course stages can help us design targeted interventions that can more effectively intervene on the links between neighborhoods and dementia.

This study makes a novel contribution to the emerging sociological research area of structural determinants of brain health. Building on conceptual frameworks in medical sociology, life course, and neighborhood effects, it compares the evidence for the cumulative disadvantage hypothesis and the sensitive period hypothesis for dementia. Using data collected from Black and white older adults who have been participating in the Panel Study of Income Dynamics (PSID) since their youth in 1968, it overcomes the measurement challenges of prior studies. Moreover, it appropriately accounts for correlated time-invariant exposures by implementing novel statistical techniques. The results provide strong new evidence that elucidates the complex dynamic between neighborhood poverty exposure and brain health, underscores the role of the life course, and provides new directions for sociologists entering this quickly developing research field.

Bourdieuian field of power and health, Thematic session – Chair: Gerry Veenstra & Mirza Balaj – Room K.202

Re-inventing the sexual field: Sexual decision making among men who have sex with men in Flanders during and after the Sars-Cov2 pandemic.

Estrelle Thunnissen (University of Antwerp), Veerle Buffel (Free University Brussels), Edwin Wouters (University of Antwerp; University of the Free State)

More than a decade ago, analytics of the sexual field was put forwards researchers of sexual culture as the best way to go beyond the market metaphor when studying the social organization of sexual relations (Green, 2011; Levi Martin & George, 2006) (Race, 2003). Simultaneously, sexual health scholars extended Grossman's concept of health capital to sexual capital, to provide insight into sexual health behavior (Michael, 2004). Since then very few studies have applied this promising framework to empirical data, despite there being many topics such as sexual risk behavior, that continue to defy other theoretical frameworks (Tan, 2019) (Wu & Trottier, 2021) (Shepherd, Denning, Elbe, Maki, & Brochu, 2023). Although there have been many studies on changed sexual behavior during the Covid-19 pandemic, most take an inductive approach and the findings remain highly descriptive (Qaderi et al., 2023). Taking a relational approach to sexual and related health practices during the pandemic can add to the body of work growing around Bourdieu's theory of practices, as well as extend the work on sexual fields and sexual capital (Veenstra, 2014).

We posit that the pandemic caused radical changes in the sexual field, with the familiar field becoming unfamiliar to its own actors. Scarcity is the driver of power, and we expect that sexual interactions became more scarce in the face of the pandemic, providing chances for power to be redistributed in the field through strategic action. We hypothesize that actors in the sexual field of Men who have Sex with Men in Flanders experienced disrupted doxa, as taken for granted understandings of dating, sexual practices and sexual health could no longer be applied without reflection and adaptation to the pandemic context. As the rules of sexual engagement changed in response to the pandemic, it is likely people became uniquely aware of what the rules were before, how to shape them through choices in the moment, and what they wanted them to be in future.

Reactions to and compliance with physical distancing rules and recommendations were extremely varied in the general population (van Schaik et al., 2024). Based on this we expect that there was not one tacit agreement on the rules in the sexual field among MSM during this period, but several competing sets. Simultaneously, decisions previously only relevant to the sexual (health) field, such as the number of partners, now had potential consequences in the health field. There has always been an influence of health habitus on sexual capital, and exchange potential between sexual capital and health capital, located in sexual health and physical attributes (Michael, 2004). Yet, we hypothesize that during the pandemic relations between health habitus & capital and sexual habitus & capital became more interconnected.

The reconstitution of the sexual field outlined above provides researchers with a unique opportunity to see the creative aspects of individual agency, as actors take strategic actions to redistribute power, acquire (new aspects) of sexual capital and actively re-negotiate rules of the field with others (Levi Martin & George, 2006). This was likely an ongoing process, as covid-discourses kept changing, physical distancing regulations were updated, treatments and vaccinations became available, and an electronic identification system was introduced showing vaccination and illness history. Finally, as the emergency phase of the pandemic came to an end in 2022, the sexual field may have re-stabilized. This presents the opportunity to study what old and new rules now govern sexual behavior, how taken for granted these rules have already become, and if actors have been able to constitute change through strategic actions during and after the pandemic.

To show how health-related practices such as covid-19 prevention techniques are subject to the logic of sexual fields and how the logic of the sexual field changes in response to health related choices, we perform an abductive analysis of in-depth interviews on the topic of sexual decision making before, during and after the Sars-Cov2 pandemic with 30 Flemish Men who have Sex with Men who have multiple partners (Tavory & Timmermans, 2014).

During our preliminary analysis we found that MSM indeed experienced a disrupted doxa, and that several new 'schools' of tacit sexual field rules developed as time went on, with interviewed MSM explicitly endorsing and complying with some and rejecting others. MSM became reflective of their own habitus because of both the disrupted doxa and the new rules they encountered. Sexual capital underwent a change from being mainly about having 'line', 'skill', and physical attraction to being about having health capital (physical distancing, vaccination, discussing pre-cautions) combined with social capital of being 'known' and 'trusted'. We will develop these early findings during subsequent rounds of coding, going back and forth between Bourdieusian theories of fields of power and empirical data, looking for surprising and contradictory findings, as stipulated by the abductive reasoning approach (Tavory & Timmermans, 2014).

Patterns of class fraction-specific spread of distinctive health-related practices

Dominik Röding (Hanover Medical School)

Introduction

According to Bourdieu's (1984) class theory, the structure of inequality is not solely characterized by vertically stratified social classes but also by antagonistic class fractions within those classes. Along the vertical axis,

Bourdieu differentiates social classes based on the volume of capital (sum of cultural, social, and economic capital), and along the horizontal axis, he distinguishes class fractions based on the composition of capital (the ratio of cultural to economic capital). He posits that class fractions engage in symbolic struggles to contest the value of different sorts of capital. Struggle for distinction would therefore not only take place between classes, but also within classes. For instance, in the dominant class the ascetic aristocratism of the 'new bourgeoisie' is antagonistic to the luxury tastes of the bourgeoisie. In the middle class, the innovative habitus of the 'new petty bourgeoisie' and the conservative habitus of the 'declining petty bourgeoisie' would oppose each other. Bourdieu also assumes the new bourgeoisie and the new petty bourgeoisie are allies in these struggles. The new petty bourgeoisie would imitate the lifestyle of the new bourgeoisie and symbolically dictate it to everyone else. Simultaneously, the new petty bourgeoisie would develop a counter-culture (e.g., alternative medicine, anthroposophy, anti-vaccination, homeopathy, para-science, vegetarian diet) to the legitimate culture of the dominant class in order to improve its position in symbolic struggles. This counter-culture is directed in particular against all class fractions that attach more value to economic capital than to cultural capital. This would imply that the practices associated with this counter-culture primarily follow a horizontal gradient along the composition of capital. This contribution investigates whether such practices are more widespread in the new petty bourgeoisie and the new bourgeoisie than in the class fractions on the other side of the space of social positions. The guiding hypothesis is that distinctive practices follow both a vertical and a horizontal social gradient.

Methodology

The hypothesis was examined with cross-sectional data from the German General Social Survey (ALLBUS; waves 2012 and 2014, $n=3,480$ and $3,471$). The Bourdieusian class schemas from Hansen et al. (2009) and from Atkinson (2017) were used and a separate Bourdieusian class schema was developed and operationalized (Röding, in review). In order to be able to evaluate the results of the analyzes with the Bourdieusian class schemas, the analyzes were also carried out with the European Socio-economic Groups (ESeG) as well with trichotomized variables on educational status and income status. The ESeG is a derivative of the well-known Erikson-Goldthorpe-Portocarero class schema (EGP). Using contingency analysis, class-, class-fraction- and status-specific differences in the spread of four distinctive health-related practices (vegan diet, eating vegetables several times a day, use of homeopathy, use of anthroposophy) were analyzed. Cramer's V and p-values were calculated.

Results

The analyzes with the three Bourdieusian class schemas uniformly show that the distinctive health-related practices examined are more widespread in the form of a vertical social gradient in higher social classes than in the classes below. On the other hand, these class schemas show that these practices are most widespread in the form of a horizontal social gradient in the class-fractions with a predominance of cultural capital and least widespread in the class-fractions with a predominance of economic capital.

In contrast, the ESeG does not identify any patterns of a class-specific spread of these practices and the two status indicators only reveal the pattern of a vertical social gradient in the spread of these practices.

Conclusion

The four distinctive health-related practices analyzed are more widespread in the new petty bourgeoisie and the new bourgeoisie than in all other class fractions. The class fraction-specific spread of these practices follows both a vertical and a horizontal social gradient. The spread of these practices can therefore no longer be explained by the volume of capital (class affiliation) alone, but must also be explained by the capital composition (class fraction affiliation). The ESeG and the status indicators are not able to reveal the horizontal social gradient. The methodological spectrum of health inequality research should therefore be expanded. The results are representative for Germany. The extent to which they can be generalized to other countries should be investigated in further studies.

A topology of health inequalities in Germany and Poland: Towards a spatial comparative approach

Stephanie Beyer (Leibniz University), Tomasz Warczok (University of Warsaw)

Health is not equally distributed across society, but depends mainly on social position, age and gender, factors that are also closely linked to different habitus, lifestyles, attitudes and tastes. Poland and Germany are confronted with increasing social inequalities and are experiencing drastic changes in their age structures which also entails changes in moral and political beliefs regarding access to healthcare and general well-being. Despite these similar challenges, the percentage of healthcare expenditure in both countries differs significantly. Against the background of these similarities and differences, we examine how health practices, attitudes as well as trust in and satisfaction with the healthcare system vary by social position, age and gender. These aspects are examined comparatively between Poland and Germany and over time.

We will use data from the International Social Survey Program (ISSP) to identify multidimensional social and cultural differences related to health in both European countries. More specifically, we use the 2011 as well as the 2021 Health and Health Care modules that include questions on health status, beliefs about health, use of alternative medicine, right to health care, health practices, and trust in the health care system. The first wave includes n=1602 individuals for Germany and n=1115 for Poland. The data release of the most recent survey is expected this spring, which allows us to compare both social spaces across time. We will map both multidimensional social spaces – the Polish and the German one – using multiple correspondence analysis (MCA) which has proven to be very insightful in the sociology of health (e.g. Antunes 2011; Balaj und Eikemo 2022; Burnett und Veenstra 2017) as it allows for a multidimensional, topological interpretation to better understand the relationship of structural factors, health, patterns of health-related practices and attitudes in Germany and Poland. In addition, we will use Euclidian clustering and class-specific multiple correspondence analysis (CSMCA) that helps us to additionally explore latent structures and differences of and among different sub-clouds with specific characteristics (such as age, gender, social class) compared to the whole social space (Le Roux und Rouanet 2010; Robette 2024).

We expect that first and foremost, people's health practices and attitudes towards the health system will differ clearly according to their position in social space as well as age. However, we suppose that despite a general improvement in health over the past 10 years, class differences in this matter have widened due to the increase in income inequality in both countries.

Making impact through multistakeholder collaboration, Thematic session – Chair: Elizabeth Pollitzer – *Room K.203*

Diversity Minimal Item Set (DiMIS) for routine data collection in empirical studies to contribute to closing the diversity and gender data gap

Gertraud Turu Stadler (University of Berlin)

Background

Despite the shared value of providing high-quality health care for all, considerable data gaps regarding gender and diversity persist in the health sciences. With a group of international experts in the Diversity Assessment Research Group, we have developed a proposal for a Diversity Minimal Item Set (DiMIS, Stadler et al., 2023) for routine data collection in empirical studies to systematically close these data gaps.

Objectives

To present results from empirical studies using the DiMIS to describe gender and diversity in student and staff samples and their relationship to well-being.

Methods

We conducted survey studies of students and staff in academic medicine and other health professions and in art students with a multi-domain approach including gender, age, socio-economic status, care work, physical and mental health and dis/abilities, sexual orientation, ethnicity, and religion and world view.

Results

We found high feasibility and acceptability of using the DiMIS in survey studies. Using the DiMIS, we were able to describe and compare gender and other diversity domains across these samples and conduct intersectional analyzes. These diversity domains were systematically related to well-being, allowing us to identify unmet needs that should be addressed in evidence-based organizational development.

Discussion

The DiMIS is a useful starting point for systematically addressing gender and diversity data gaps and allows for intersectional analyzes. We will discuss ideas for integrating it into theory building and the study design process, as well as data analytic approaches to analyzing the resulting multi-domain diversity data. We will also present some challenges and lessons learned regarding data protection and open science practices. Using systematic diversity assessment tools for routine data collection in the health sciences facilitates a better understanding of the heterogeneity in patients and health care providers that is the basis for more innovative research and personalized health services for all.

Fostering research excellence: Integrating gender and intersectionality in doctoral training in Québec

Janice Bailey (Research Fund Québec), Fanny Eugène (Research Fund Québec)

It is well established that diversity contributes positively to research outcomes. As a public research funding agency, the *Fonds de recherche du Québec* (FRQ) has directed its efforts towards both (1) the research community and (2) the research process. These two areas are interconnected, as diversity among the investigators involved in planning and conducting research is inherently associated with diversity in what and how research is conducted. Indeed, it has been shown that female researchers are more likely to report gender disaggregated data when they publish their results. Similarly, there is a relationship between the intersectional identities of researchers and the topics being studied, indicating that more diversity in the research community would be related to more diversity in the knowledge generated by research. The FRQ, however, expects that all researchers consider gender and intersectionality in their projects when appropriate. Research becomes more robust and impactful when it acknowledges the diverse realities, concerns, and needs within society. By considering this diversity, not only does it promote fair outcomes, it also enhances the overall quality of the research.

To make gender and intersectionality standard practice in research culture, they need to be included in doctoral training. Therefore, the FRQ is exploring how weaving these aspects into our programs can enhance diversity in training and research across all fields. For instance, the FRQ co-developed dedicated funding opportunities with Indigenous communities in the province of Québec to encourage students to pursue postsecondary training. We have also adjusted our graduate and postdoctoral scholarship programs to raise awareness and encourage the consideration of diversity in research projects submitted. The *Fonds de recherche du Québec – Nature et technologies* supports 35 strategic clusters in a range of scientific fields. Each of these clusters has developed their own strategy to facilitate research diversity, thereby raising awareness of these issues to thousands of students across the province. Feedback received from the FRQ's research community in response to these initiatives has been generally positive, however, we have encountered resistance from a small but well-organized and influential group of researchers. The insights gained from such debates have enabled us to refine our efforts, hopefully resulting in enhanced effectiveness.

Advancing innovation opportunities for women's health

Maike Scharp (Bill & Melinda Gates Foundation), Jamie White (US NIH Office of Research on Women's Health)

Globally, Women's Health R&D is a neglected area of research and investment. This is demonstrated both by the limited amount of funding dedicated to female-specific health topics (e.g., female contraceptive technologies, gynecological diseases, menstruation, and menopause); as well as a lack of attention to women-specific solutions within areas that are otherwise well funded in R&D (e.g., cancer, HIV) or communicable and non-communicable diseases that effect women differently (e.g., cardiovascular, pain) or disproportionately (e.g., mental health, autoimmune). To improve women's health across the life course for diverse lived experiences, it is critical to elevate areas of women's health research within the global R&D agenda and devise approaches to address areas of need with a focus on intersectionality and health equity.

To address this gap, the Bill & Melinda Gates Foundation and the National Institutes of Health initiated the Innovation Equity Forum a group of 250+ experts and stakeholders from 50+ countries. The goal of the Innovation Equity Forum is to:

- Convene a global community of stakeholders and gatekeepers of health innovation around Women's Health R&D
- Mobilize and accelerate innovations to improve women's health through shared understanding of select critical women's health R&D priorities
- Foster cross-sector multinational partnerships to advance R&D efforts in women's health innovation through enhanced coordination and the development of the Women's Health Innovation Opportunity Map 2023

Though an inclusive, consultative, cross-sector effort between January and October 2023, the Innovation Equity Forum generated the Women's Health Innovation Opportunity Map 2023 as a collaborative framework to advance women's health innovation.

This Opportunity Map lays out 50 opportunities across 10 topics that were identified using an adapted Child Health and Nutrition Research Initiative (CHNRI) methodology followed by stakeholder-driven discussions in a six-step process incl. 1) topic and criteria selection, 2) opportunity generation, 3) opportunity consolidation, 4) scoring against PRIME criteria (Potential for impact, Readiness to scale, Innovation feasibility, focus on what Matters to women, and ability to improve health Equity, 5) selection of 50 prioritized opportunities through live discussions at the IEF convening in July 2023 and 6) development of solution strategies for each opportunity, that articulate actionable ways to realize each opportunity and create impact within the next 15 years. As such, this Opportunity Map provides a guide that stakeholders across the women's health R&D ecosystem—from researchers to entrepreneurs, investors, government bodies, biopharmaceutical companies, civil society, and more—can use to advance high-impact investments and initiatives to improve women's health based on their specific sector or collectively together.

The Women's Health Opportunity Map 2023 was officially launched in October 2023 at the Grand Challenges Annual Meeting in Dakar, Senegal and featured at several key events, including the National Academies of Medicine Annual Meeting in Washington, DC and the World Health Summit in Berlin, Germany in October 2023 and the at the WHO Executive Board Session in January 2024.

A request for proposal issued in relation to the Opportunity Map by the Bill & Melinda Gates Foundation in October 2023 to kickstart innovations and ideas that address opportunities outlined in the Opportunity Map, received 1,683 applications – the highest number of applications in Grand Challenges history with grantees announced in Q2 2024. The hope of this funding opportunity is to jump start investment in women's health equity.

4 July

4 July: 8:30 – 10:00

Intersectional Perspectives on Family Health, Thematic Session – Chair: Nadine Reibling – *Room K.101*

What a ‘Good Mother’ Eats: Food Choices, Sacrifices and the Politics of Provisioning

Charumita Vasudev (Lancaster University), Swayamshree Mishra (Indian Institute of Technology Kanpur), Ankita Rathi (Lancaster University), Jasmine Fledderjohann (Lancaster University), Sukumar Vellakkal (Indian Institute of Technology Kanpur)

Introduction

The biological act of ‘giving birth’ has been intensively socially constructed and performed around the deeply gendered and socially pedestalized idea of ‘motherhood’. For feminists, the concept of motherhood has always been contested- one that often oscillates between the ambivalence of ‘power’ and ‘powerlessness’ (Krishnaraj, 1995). In the Indian context too, the ideals of ‘motherhood’ have been central not only in the colonial and post-colonial nation building process-with the mythical feeding into the ideological reading of it as an icon, but also in the reality of women’s everyday lives as reproducers of both the dominant elite and the laboring poor (Bagchi, 2017). Gilroy (1987) argues that not only are families the nation in microcosm, but they act as the means to turn social processes into natural instinctive ones. Mothers thus, come to reproduce the patriarchal values of the dominant class/ race. More specifically, in Indian context, mothers of sons came to occupy a position of power as gateways to the caste system (Chakravarti, 1992;2004). Consequently, mothers also engage in the work of status production (Papanek,1992) to aid the social mobility goals of families by, among other things, raising children who are upwardly mobile.

In this complex and enmeshed background, this paper centers on one of the most conspicuous and routine gendered expectations from mothers- the ‘duty’ to provide food to families. The paper studies some everyday decisions like what to cook, how much to serve and to whom, who eats first, who eats last, whose food preferences are prioritized etc. to understand the intra-household dynamics and the politics of provisioning within families. We argue that while on one hand mothers make these decisions keeping the social mobility goals of families in sight, on the other hand, they also make food consumption choices for themselves compromising on nutrition while ‘bargaining with’ the socially constructed ideals of ‘good mothers’.

Research questions

- 1) What do the social constructions of a ‘good mother’ mean with respect to managing food for the family.
- 2) What do these external social pressures/norms mean for food consumption of mothers and distribution among children of both genders within households. How do children understand these decisions?
- 3) How are negotiations with food related to social mobility goals of families? Who is responsible for these negotiations?

Methods

This research is a component of the broader project, Food Security for Equitable Futures, which investigates food insecurity in the Global South using mixed-methods. We gathered qualitative data from 87 households in Uttar Pradesh and Goa, concentrating on demographic particulars and infrastructure details using a household survey and semi-structured interviews (with multiple household members). Employing purposive sampling and snowballing techniques, we ensured a diverse sample based on caste, religion, location, and family structure.

For this paper, we specially focus on narratives of mothers, to study factors influencing food-related decision-making within households. Interviews are coded using NVivo for thematic analysis. We also use narrative analysis of qualitative data to further delve into the perceived responsibilities and notions surrounding motherhood and how it affects women's interactions with food.

Conclusion

We study how motherhood is performed in to 'protect' and 'nurture' in consonance with and often in negotiations with the socially constructed ideals for 'good mothers'. We explore how women's choices for themselves are deeply colored by the socially pedestalized ideals of 'sacrifice' and putting themselves last.

We find that since mothers are the ones considered responsible for the family's food, it often means that they eat less than their hunger (save for others or eat at last), skip a meal or eat only Rotis/Roti and 'chutney'/ Rice and salt etc. to effectively manage and distribute the food cooked at a particular time in addition to subjugating own desires/ needs to that of the family. We argue that this sometimes leads to a self-created deprivation amongst mothers and negatively impacting food access and uptake, consequently their health and well-being. This becomes even more severe in case families are facing financial stress that can come with a wide variety of external factors- ranging from crop losses and inflation to family illness or distress due to job loss. Extreme examples were noted during the time of Covid when families were surviving on bare minimum and women were deliberately going hungry to save some for the next day.

In the Indian society, women often assume a position of power as mothers of sons, compared to mothers of only daughters. We explore if this has an affect on the food provisioning decisions that the mothers make for themselves and children of both the genders. We study how these decisions are perceived, by children, particularly by daughters in the families and if daughters come to emulate and pedestalize these ideas of sacrifice and socially reproducing them in later stages. In this context, we note that religious fasting and vegetarianism are performed mostly by women in the families, across castes. We argue that the adoption of vegetarianism by mothers in households that consume meat and this being emulated by daughters serves the dual purpose. While on one hand this aids the social mobility goals of families by asserting ritual purity, on the other hand it prioritizes more nutritious, higher valued foods towards the 'more productive' male members of the household.

Secondly, we explore how children, particularly daughters view mother's sacrifices- of eating at last or not eating and prioritizing others needs over one's own. Several young daughters are the only vegetarians or the only ones observing religious fasts in their families. The paper seeks to draw emphasis on how girl children might be adopting ritually 'pure' aspirational practices from school and other social circles as well. This too, on one hand further cements the relations of 'sacrifice' and 'purity' with notions of ideal femininity and motherhood and is an assertion of ritual purity which might later aid goals of socially hypergamous marriages and by extension the social mobility goals of families. On the other hand, it serves the related end of limiting consumption of higher value nutritious food items to men of the household, thus de-prioritizing women's health and nutrition.

Life course outcomes of individuals growing up with a sibling with a disability.

Lara Bister (University of Bocconi; University of Groningen; University of Helsinki), Nicoletta Balbo (University of Bocconi), Hanna Remes (University of Helsinki), Elena Neri (University of Bocconi), Pekka Martikainen (University of Helsinki; Max Planck Institute for Demographic Research)

Background

Research suggests that growing up with a sibling with a disability may substantially affect individuals' social, demographic, and economic trajectories, often leading to life course disadvantages. However, findings are scarce and based on small convenience samples.

Aim

This study explores life course trajectories from adolescence to early adulthood (such as educational outcomes, leaving of the parental home, family formation, and health) of individuals who grew up with a sibling with a (sensual, physical or cognitive) disability.

Methods

Using full-population Finnish register data, we compare the life course outcomes of those who grew up with a sibling with a disability with their counterparts who did not, matching on individual and family sociodemographic characteristics.

Expected results

We envision siblings of disabled individuals to be polarized in their outcomes, either being highly performing or very vulnerable.

Contribution

Our study will be the first to provide a comprehensive overview of how demographic processes may be influenced by disabilities in the family and thereby will make a significant contribution to understanding the far-reaching family consequences of disability.

Application of the Information-Motivation-Behavioral Skills Model to ART adherence in people living with HIV

Lorraine Tanyaradzwa Dube (University of Western Cape), Lucia Knight (University of Cape Town)

Background

The success of any anti-retroviral therapy (ART) program depends on adequate adherence. High adherence rates $\geq 95\%$ are required in order to achieve positive virologic suppression, increased CD4 count and fewer hospitalizations. The Information-Motivation-Behavioral Skills (IMB) model is a behavioral theory model used to assess adherence and provides a simple explanation for complex health behaviors. This paper aims to describe ART-related information, motivation and behavioral skills among people living with HIV (PLWH), as well as adherence to ART.

Method

Baseline data on ART-related information, motivation, behavioral skills and adherence was collected within a randomized controlled trial with 316 PLWH in 12 sub-districts in Cape Town, South Africa, from May 2021 to May 2022. The data was analyzed using SPSS (version 28) for descriptive statistics. Chi-squared test of independence was used to assess the relationship between the model constructs and demographic characteristics (age, gender and level of education), as well as adherence.

Results

High ART-related information was reported, with 78.5% of PLWH scoring above 60%. ART-related personal motivation was low ($M = 2.04$ on a 1-5 scale, $SD = 0.89$), ART-related social motivation was high ($M = 3.74$ on a 1-5 scale, $SD = 0.55$), household social support was high ($M = 72.5$ on a 0-100 scale, $SD = 25.12$) and ART-related behavioral skills were high ($M = 4.13$ on a 1-5 scale, $SD = 0.53$). 85.4% of PLWH self-reported as adherent to ART, based on four day recall. There was no statistically significant relationship between each of the model constructs and age, gender and level of education. Adherence was significantly related to household support and behavioral skills ($p = 0.01$ and $p = 0.01$, respectively), but not to information or motivation.

Conclusion

The results underscore the need to enhance personal motivation in order to improve adherence. Behavioral skills are important in promoting adherence, in agreement with the IMB model. Household-based social support has

also emerged as an important contributor to adherence. The use of theory-based models to understand factors that influence ART adherence directly and indirectly helps to optimize adherence for PLWH. Use of these models acknowledges the need for a comprehensive approach to effect behavior change.

Sickness-related attendance behavior as reactance to experienced parental workplace discrimination

Joachim Gerich (Johannes Kepler University Linz), Martina Beham-Rabanser (Johannes Kepler University Linz)

Introduction

As in many other countries, parental workplace discrimination (PWD) defined as unequal treatment of employees (e.g. regarding hiring, remuneration, promotion, and other working conditions) based on actual (or inferred prospective) parental status is forbidden by Austrian law. Nevertheless, a lot of workers face unequal treatment related to parental status.

Although PWD has gained attention in recent research (Becker et al., 2019; Hipp, 2020; Shen and Dhanani, 2018; Wochenalt and McGrew-Taferl, 2020) there is a distinct lack of studies on possible effects of such unequal treatments on health and health-related behavior such as sickness presenteeism (SP) defined as working while ill (Ruhle et al., 2020).

Our research aimed to analyze the association between experienced PWD and health and SP of employees based on a theoretical model that combines stress-theoretical explanations with assumptions following reactance and injustice theory. Meta-analytic research on discrimination related to race and sex (Jones et al., 2016; Lee and Ahn, 2011) confirmed evidence for the negative effects of discrimination on physical and mental health. Also, prior research confirmed SP to be positively related to experienced discrimination based on ethnicity, age, education, religion, and sexuality (Cho et al., 2016; Deng et al., 2020; Miraglia and Johns, 2016; Yang et al., 2016). Typically, stress-theoretical explanations are proposed regarding mechanisms linking discrimination with impaired health and SP. Stress resulting from experienced discrimination is thought to increase vulnerability and, subsequently increase rates of sickness absence and SP. However, other findings (Manuel et al., 2017) confirmed that unequal treatment is related to increased SP mediated by poor health, but unrelated to sickness absence. Hence, other additional mechanisms beside the stress induced health-impairment path must be considered to explain the shift from sickness absence to SP associated with experienced discrimination.

Experimental research on PWD (Heiserman and Simpson, 2022) found that – although those who experienced discrimination gave worse job ratings, reported less interest and a lower status position – discrimination was unexpectedly related to higher job performance compared to a control group without experienced discrimination. Reactance theory (Brehm, 1966; Kray et al., 2001) may be employed to explain this result, where individuals who perceive that their ability and motivation is questioned increase their efforts to disprove stereotypes against them. Thus, increased SP associated with experienced PWD may be expected to be a type of self-endangering behavior (Dettmers et al., 2016), defined as a problem-focused coping strategy, where the maintenance of productivity and organizational reputation is prioritized over health in order to disprove stereotypes regarding low performance and unreliability. Moreover, we expect that health-related effects and self-endangering behavior following PWD will be more pronounced in individuals who appraise PWD as inappropriate and unfair because this will amplify the perceived need to counter inappropriate stereotypes held against them.

Methods

We present results based on survey data (n=347) collected from a random sample of employees in their reproductive age (between 20 and 45 years of age). The sample was drawn from the register of the Upper Austrian Chamber of Labor, which covers the vast majority of employees in the region of Upper Austria. We used 49 items that scoped respondents' experience with PWD grouped by different modalities and biographic stations. Appraisal of PWD was measured with ratings of two fictional cases presented to respondents.

Results

We found that PWD experienced during an occupational biography is related to impaired health indicated by an increased number of days with sickness. However, the increased number of sickness days was not mirrored in the number of sickness absence days, indicating a substitution of sickness absence by SP. In accordance with that finding, we confirmed a significant association between experienced PWD and increased SP-propensity, which is a measure estimating individuals' tendency to decide for SP instead of sickness absence on days with health complaints. Moreover, we confirmed an interaction effect for respondents with own children in that PWD is related to an increased SP-propensity when individuals deny arguments justifying discrimination, but PWD was unrelated to SP when individuals align with such justifications.

Conclusion

We found evidence that experienced PWD acts as a “double risk factor” (Aronsson and Gustafsson, 2005) that increases the risk of illness and, at the same time, increases a shift from sickness absence to SP. We argue that a stress-theoretical explanation is a suitable approach in explaining the health-related pathway. In addition, we assumed that SP is also driven by a reactance behavior to counter inappropriate stereotypes held against an individual. From such a perspective, SP is explained as a self-endangering behavior where individuals intentionally prioritize the maintenance of their goal attainment, career prospective, and organizational reputation over health to disprove stereotypes regarding low reliability and performance held against them. Such reactance behavior seems to be especially prevalent in those individuals who perceive PWD as inappropriate but less prevalent in those who accept justifying arguments for PWD.

End of Life, Regular Session – Chair: Deborah De Moortel – Room K.102

Varieties of uncertainties in the interaction of healthcare professionals, caregivers and patients in the gynecology department in the context of a serious, incurable disease: The role of general nurses

Eliška Vokřálová (Charles University)

Background

The treatment of serious incurable diseases brings a number of uncertainties that affects thinking and actions of healthcare professionals, patients and their caregivers (Etkind, Koffman, 2016). Communication, which is focused on incurable diseases, can indicate uncertainties, due to which important pieces of information are hidden in confusing euphemisms or these kind of conversations does not take place at all (Krawczyk, Gallagher, 2016). The problem of uncertainty is important in the context of serious illnesses, in which many patients are unaware of the availability of advanced care (Hagan et. al., 2018). These problems are potentially dealt with thanks to the composition of palliative care teams, made up of different professionals, each with a specific role, and this contributes to the comprehensive approach to patients and their caregivers (Bowen, 2014). Among healthcare professionals, general nurses are able to discuss the option of advanced care, explain what palliative care entails (Hagan et. al., 2018). Furthermore, they can provide information to patients about what treatment means individually for each of them (Lind, 2019; Bach et. al., 2009; Peden-McAlpine, et. al. 2015) and actively seek to engage in conversations with patients about care planning and disease prognosis (Hjelmfors, et al., 2015).

Against this backdrop, the aim of this study is to find out and describe the multi-layered (diversity) of uncertainty, occurring in the interaction between patients with serious, incurable disease, their caregivers and healthcare professionals. Therefore, this study aims to disentangle the complex of uncertainties, in the context of palliative care, focusing more specifically on how general nurses deal with uncertainty and what mechanisms and strategies they use.

Methods

The topic is investigated using a qualitative, ethnographic approach. A combination of participant observation and semi-structured interviews is used for data collection. The plan is to make at least 30 hours of observation

and about 12 of semi-structured interviews during five months from February to June 2024. The second part of the research will be held for at least another five months from July to December 2024. Participant observation enhanced an in-depth understanding of the mechanisms of managing uncertainty by research participants. The observations will be recorded in a note sheet and supplemented by keeping a diary of the researcher, which also allowed to reflexively engage with the hybrid researcher's/nurse position.

The techniques of open, thematic and selective coding were employed to analyze the data. The research study was approved by two Ethical Committees - Faculty of Social Sciences UK and the General University Hospital in Prague.

Results

The study demonstrates the complexity and multi-layered nature of uncertainty occurring in the interaction between healthcare professionals, patients and their caregivers in the context of a serious, incurable disease. The study also identified the communication method used to convey information about palliative care team involvement.

Conclusions

A serious incurable disease brings with it a number of uncertainties that appear not only for patients, but also for caregivers and medical staff. These uncertainties have different forms and it is often not easy to work with individual types of uncertainties. In the normal day-to-day clinical practice, staff members of hospital facilities do not have the amount of time and capacity to provide patients and their caregivers that they would like to have. General nurses spend a great deal of time with patients and their caregivers and play an important role in their relationship. The trustful relationships they build with patients and their caregivers allows them to cope with different aspects of uncertainty that they encounter. They represent an important connecting element of communication, bridging patients, their relatives and other members of the palliative team.

Navigating unmet care needs: Assessing the impact of long-term care policies at the end of life in Europe

Hazal Swearingen (Cankiri Karatekin University), Gulcin Con Wright (TED University)

Introduction

European countries are undergoing population aging as a consequence of an extended life expectancy and continued declines in fertility rates. This aging population has specific and a variety of needs, particularly pertaining to their health and well-being. One of the health issues that become more prominent with age is about ADL/IADL limitations. In Europe, 10.4% of men and 12.8% of women aged 50 and older have at least one ADL limitation, while 13.4% of men and 21.2% of women have at least one IADL limitations. Alarmingly, more than half of this demographic group experiences unmet care needs. Existing literature also reveals a strong association between unmet I/ADL needs and long-term care systems (social care). However, there is limited understanding of how I/ADL care needs are addressed at the end of life and whether long-term care systems play a role in this outcome. Verbakel et al. 's typology (2023) categorizes various types of long-term care (LTC) policies in European countries based on macro-level indicators such as (1) supported familialism, measured by the availability of informal caregiver support and cash benefits to caregivers; (2) supported defamilialization through the market, involving cash benefits to care users; and (3) defamilialization through public provision, assessed by the relative number of LTC beds and the number of formal LTC workers. Based on this typology, this study investigates the prevalence of end-of-life I/ADL unmet care needs of older adults based on the indicators of long-term care policies of a country.

Methodology

We utilize data from nationally representative surveys of older adults in Europe obtained through the Harmonized End of Life data provided by the Gateway to Global Aging Data. The Survey of Health, Ageing, and

Retirement in Europe (SHARE) conducts surveys among adults aged 50 and older in 29 European countries. To gather information about respondents' experiences prior to death, SHARE conducts end-of-life interviews with a knowledgeable proxy, such as a spouse or child. The analytic sample for this study includes respondents from 17 European countries (Austria, Belgium, Czech Republic, Denmark, Estonia, France, Germany, Greece, Hungary, Italy, Luxembourg, Poland, Portugal, Slovenia, Spain, Sweden, Switzerland) after excluding 12 countries for either not having deceased older adults with I/ADL care needs or for not being included in Verbakel's typology. We use the corresponding Waves 6-8 (2015–2018) of the Harmonized HRS End of Life dataset (N = 3,729). In this study, descriptive analyzes are conducted and weighted hierarchical analysis will be conducted in line with the typology developed by Verbakel et al. (2023).

Results

The preliminary results show that in the overall sample, on average, 7.29% of older adults had any unmet needs, 4.51% had unmet ADL needs, and 4.26% had unmet IADL needs. The availability of cash benefit to informal caregivers and more LTC beds, on average, across countries is associated with higher risk for unmet needs. 6.97% of older adults in countries without cash benefits to caregivers, and 8.28% of older adults in countries with cash benefits to caregivers have unmet needs. 8.45% of older adults in countries with more than average LTC beds for older adults, and 6.25% of older adults in countries with less than average LTC beds for older adults have unmet needs. However, caregiver support does not make a significant difference in the prevalence of unmet care needs. 7.31% of older adults in countries without informal caregiver support, and 7.28% of older adults in countries with informal caregiver support have unmet needs.

Conclusion

This study investigates the prevalence of unmet I/ADL needs of older people approaching the end of their life in relation to a country's long-term care policies. Preliminary results indicate that the provision of cash benefits to caregivers is associated with higher unmet needs even though informal caregiver support has no effect on unmet needs. Furthermore, the availability of more than average LTC beds is also associated with higher unmet needs. Further analyzes will enable us to draw conclusions about the prevalence of end-of-life I/ADL unmet needs based on a country's long term care policies. This study aims to gain a better understanding of end-of-life care needs of older people and how certain indicators of long-term care policies either mitigate or increase the risks associated with these unmet needs. Considering that the end of life is a period in which health status and related needs of older people show the greatest variability, it is critical to examine needs associated both with different limitations and the availability of social care provisions. The inclusion of older people with a wide variety of care needs and health limitations would also allow for better social policymaking on long-term care arrangements.

Death as great equalizer? Socio-economic gradients in professional end-of-life care support for older adults in Europe

Jürgen Maurer (University of Lausanne), Thibault Gitz (University of Lausanne), Clément Meier (University of Lausanne)

Introduction

The end of life often presents an extraordinary challenge not only for the terminally ill persons but also for their relatives and friends. Moreover, in most European countries, older adults state that they prefer to die at home than in a hospital or other institutional setting. However, providing the often needed care near the end of life without any professional help can lead to lower quality of care and increased burdens on the family caregivers who cannot rely on additional professional support. At the same time, professional support near the end of life is often not readily available and if it is, it is often not straightforward to access and rather costly. This paper assesses socio-economic gradients in the receipt of professional support for older adults with activity of daily living (ADL) limitations near their end of life using data from 27 European countries and Israel from the Survey of Health, Ageing and Retirement in Europe (SHARE).

Methodology

We use data regarding the end-of-life circumstances of around 9,000 deceased participants of SHARE, which were obtained through informant interviews (“exit interviews”) following participants’ deaths. We use multivariable regression models to assess the partial association of receiving some professional support with ADL care near the end of life with the deceased persons’ previously reported level of education and subjective financial status as main measures of socio-economic status. Our models also include other individual-level controls such as age at death, family composition, cause of death and intensity of care need among others, country-level controls such as countries’ GDP and public expenditures on long-term care and/or country-level fixed effects.

Results

First results indicate significant within-country and cross-country gradients in the receipt of professional help with ADL limitations near the end of life. Individuals with lower levels of education and higher reported difficulties to make ends meet are significantly less likely to receive any professional help with their ADL limitations near their end of life. Moreover, absence of any professional help with ADL limitations near the end of life is also more common in countries with lower GDP and who spend a lower share of GDP on public long-term care support.

Conclusion

We document significant socio-economic gradients in the receipt of professional support for end-of-life care in Europe, which are likely to reflect important financial and non-financial barriers to accessing professional help for people at their end of life. Improving awareness of potential professional care support services and ensuring their affordability for the entire population should be key priorities in public health policies for end-of-life care in Europe. As in many end-of-life studies, challenges of sample representativeness and corresponding issues of external validity are key challenges of our analysis.

‘I just want to survive, I don’t want to die’: Theorizing experiences of parallel planning for young adults with life-shortening conditions

Sarah Earle (Nottingham Trent University), Maddie Blackburn (Nottingham Trent University), Lizzie Chambers (International Children’s Palliative Care Network), Julia Downing (International Children’s Palliative Care Network), Kate Flemming (University of York), Jamie Hale (independent), Hannah Marston (The Open University), Lindsay O’Dell (The Open University)

Introduction

Young adults with life-shortening conditions are a relatively new population; until recently they were not expected to survive childhood. However, advances in medical treatment and care mean that many such children are now reaching adulthood. However, while life expectancy may have increased for some, this is by no means certain. As such, people with life-shortening conditions and their families are encouraged to engage in the process of ‘parallel planning’; this refers to planning for the best (a long and healthy life) *and* the worst (end-of-life). Although parallel planning is a policy imperative and is understood to be normatively good very little is known about how and why young adults with life-shortening conditions engage in parallel planning and the meanings this holds for them. In this paper we draw on interview data from a study exploring the experiences of young adults with life-shortening conditions during the first wave of the COVID-19 pandemic in the UK, exploring their views and experiences of parallel planning during a time of personal and global crisis where talk of death and dying were heightened.

Methodology

This paper is based on a qualitative research study co-produced by a multi-disciplinary team that included three experts by experience (young adults with a life-shortening condition) and three partner organizations (Together for Short Lives, Hospice UK and the International Children’s Palliative Care Network). Drawing on an interpretive philosophical framework, the study is informed by constructivist Grounded Theory Methodology (cGTM) which

assumes that data are generated through a reflexive process of co-creation. Participants were recruited to the study using both purposive and theoretical sampling. Methods of recruitment included advertising in the newsletters of our partner organizations, social media and the professional, academic, and social networks of the research team. Data were generated using in-depth guided interviews held online and analyzed iteratively using the constant comparative method. Interview conversations were wide ranging but focused on addressing our central research questions: What are the unintended consequences of pandemic control on the lives of young adults and their families? Approval for the study was given by The Open University's Human Research Ethics Committee in June 2020.

Results

We interviewed 26 young adults aged 18-40 years with a life-limiting condition living in the UK. Of these, 17 were women and nine men. Eighteen participants described themselves as White British or White Other, three as British Asian, two as Black British, two as Mixed Race and one as Latin American. Participants were located across the four countries of the UK but the majority (n=21) were living in England. We also interviewed 12 family members, but their data are not reported here. Through our analysis of the data we identified four core categories that explain whether, and how, participants engaged with the concept and process of parallel planning. These were 'planning is for all', 'plan and put aside', 'keeping safe and surviving' and 'planning to survive'. These four categories represent different ways of approaching and understanding parallel planning in the context of two key disruptors. The first disruptor refers to their life-shortening condition and the effect of this on their lives including the management of long-term chronic illness and disability, and acute and unpredictable life-threatening illness episodes. The second disruptor refers to the societal context, specifically the pandemic, but more generally also, to the systems, structures and processes that govern the lives of those who live with complex medical conditions and impairments. Through our analysis we seek to explore the ways in which the meanings ascribed to the concept of parallel planning center around the preservation of self within the context of individual and societal disruption.

Conclusion

This study addresses a gap in knowledge concerning the views and experiences of young adults with life-shortening conditions on the process of parallel planning. The study challenges the conventional wisdom that conversations about parallel planning should not take place during a time of crisis. We provide evidence that the opposite may be true; that it is during crises that individuals may more receptive to considering what is important to them about end-of-life and death and so may be a good time to introduce or discuss parallel planning. All studies have strengths and limitations, and this study is no exception. For example, we were limited in our methods of recruitment and data generation due to the constraints in place during the pandemic. In addition, although people with learning disabilities are a large proportion of those with a life-shortening condition, we were not able to include them in this research. In summary, this study theorizes how and why young adults with life-shortening conditions engage in parallel planning or not, and the meanings this has in the context of a disrupted and uncertain life course.

Sexual and Reproductive Health, Regular Session – Chair: Anna Wallays – Room K.103

Abortion Trajectories, Timing, and Access Study (ATTAS)

Anna Wallays (University of Antwerp), Sarah Van de Velde (University of Antwerp)

Background

This study explores the trajectories of women presenting for abortion in Flanders, Belgium. In Belgium, as is the case in most high-income countries, there has been a noticeable trend toward abortion at less advanced gestational ages in recent decades. However, patient records from abortion centers show that women present for abortion at a wide range of gestational ages, ranging from three weeks to full term. While abortion is generally a safe medical procedure, this procedure carries greater risk when performed at more advanced gestational ages.

Therefore, it is crucial to develop a better understanding of the trajectories toward abortion and the barriers experienced within. This understanding will help explain the differences in gestational ages when individuals present for abortion, taking into consideration the social gradient involved. The study has two primary objectives. First, it aims to map the duration of the various stages of the abortion trajectory for women presenting for abortion in Belgium. Second, barriers that cause delays within these stages will be identified.

Methods

Data were obtained from the ATAS project, which collected data from all women seeking abortion care at one of the Flemish abortion centers; specifically, the LUNA centers located in Ostend, Ghent, Antwerp, and Hasselt, as well as the VUB-Dilemma center in Brussels during the fall and winter of 2023-2024. Ethical clearance for the described research was obtained from the University of Antwerp's Ethics Committee for the Social Sciences and Humanities (reference numbers: SHW_2023_48_1 and SHW_2023_48_2). Cases were included in the analysis only when the questionnaire was completed for at least 75%. A link was established with the abortion centers' database to gain insight into the sociodemographic characteristics of the sample. Based on a sample size calculation, we aimed to draw a study sample of at least 360 women from the total patient population.

Results

The collected data provides a dataset on the abortion trajectories of Flanders women who presented for abortion. Preliminary results show that a considerable number of women experience difficulties suspecting an unplanned pregnancy. This can be due to various reasons such as not immediately linking the symptoms to a possible pregnancy, mistakenly believing it is hard or impossible to get pregnant in their particular situation, and underlying reasons such as the use of contraceptives, a history of infertility, and misconceptions about age-related fertility. Additionally, over one-third of women who completed the questionnaire up to now first had a consultation with a GP before they contacted the abortion center, which lengthens the trajectory. We also found that around 40% of the respondents indicated feeling ashamed or disappointed in themselves when making a decision about the pregnancy. However, 94% indicated that their decision was set at the time they completed the questionnaire. Around 46% experienced fear of the procedure and associated pain.

Conclusion

To our knowledge, this is the first study within the Flemish context to investigate abortion timing, access, and trajectories. Furthermore, this study is highly topical given the ongoing public and political debates on Belgian abortion legislation.

Pain in medication abortion: A question of sexual and reproductive justice

Carrie Purcell (The Open University), Victoria Newton (The Open University), Fiona Bloomer (Ulster University), Lesley Hoggart (The Open University)

Introduction

Pain in the context of sexual and reproductive health (SRH) is under-theorized in medical sociology and adjacent disciplines. Some specific areas have established bodies of literature, notably around childbirth and its medicalization (for example: Oakley 1980, Davis-Floyd 1994, Crossley 2007, Shabot 2021). However, pain is in many cases addressed obliquely rather than foregrounded. The literature on women's sexual difficulties, from Tiefer (2001) onward, addresses pain more directly, but typically takes a biopsychosocial focus that leans heavily on social psychology. Pain has been addressed explicitly in relation to chronic conditions such as endometriosis (Denny 2018), though reducing endometriosis to a condition of 'reproductive health' is also acknowledged to be problematic. While key contributions to sociological theorizing of intersections of pain and gender, initiated by Bendelow (2000), have included childbirth, other areas such as abortion, intrauterine contraceptive placement, and assisted conception have drawn little sustained attention.

One context in which physical pain can be acute is medication abortion, one of the most commonly accessed SRH procedures. Self-management of early medication abortion (EMA) comprises an increasing proportion of abortions in the United Kingdom (UK) and elsewhere. In the UK, this has necessitated reconsideration of how pain is addressed, as women and pregnant people increasingly undertake the medication abortion process without direct health professional supervision. This is in part underpinned by normative assumptions that pain is a necessary or unavoidable part of that process (Authors *under review*). Pain is a contributing factor in negative experiences of abortion, and thus a potential barrier to equitable access, acutely so for those experiencing the greatest socioeconomic disadvantage. As such, abortion pain becomes an intersectional issue of sexual and reproductive justice (SRJ).

Methodology

This paper introduces one case study from a larger project on SRH-related pain. A reproductive justice lens is utilized as a means of grounding a broader exploration of SRH-related pain and the nexus of gender and health inequalities at which it sits.

As part of a study of abortion experiences during the Covid-19 pandemic, we conducted telephone interviews with twenty people living across the UK who had sought abortions during pandemic restrictions. Existing literature informed a flexible topic guide, and we took a narrative storytelling approach to data production. We asked participants to recount their 'abortion story' in as much detail as possible, from learning they were pregnant to the time of the interview. Follow-up questions clarified key information, where absent. Recruited through social media and a targeted advertisements, participants were aged 22-43, and all self-identified cisgender women.

Since inductive thematic analysis from the broader study highlighted pain as a prominent feature of the data, subsequent focused coding, and an iterative process of interpretation, were used to develop four sub-themes: expected pain is manageable for some; the problem with unexpected pain; pain (co)produces fear; problematizing 'period-like pain'.

Results

Our analysis highlights that EMA pain experiences varied. For some, pain was manageable, particularly where it aligned with expectations, though some expectations were highly negative. For others, pain was much worse than anticipated, underlining the importance of effective expectation-setting. Participants aligned EMA pain with punishment, described it as 'excruciating', a source of significant worry, and as something they could not go through again. Physical pain was also closely intertwined with emotional distress. Cultural silences around abortion (exacerbated in this case by isolation associated with the pandemic context) were seen as contributing to unclear expectations around EMA pain, which in turn generated fear. Interviewees expressed incredulity that a healthcare procedure which was proceeding normally could be so intensely painful. Likening the EMA experience to 'period pain' is potentially misleading and a source of further uncertainty.

From an SRJ perspective, our findings indicate a need to improve information provision around abortion pain (particularly in self-management), in order to reduce unnecessary distress for those seeking routine SRH care, and to minimize potential barriers to future use of SRH services. As use of medication abortion increases, our findings also highlight an urgent need for improved pain management options for this commonly accessed procedure.

Conclusions

An SRJ lens highlights the impact and implications of abortion pain as a source of gendered inequity in healthcare, in which pain experienced by women and other people with a uterus, in the course of routine SRH care, may be framed as unavoidable and something to be endured. While a limitation of this work is that data were generated early in the Covid-19 pandemic, learning from that time nonetheless has longer-term relevance. Key areas for action include avoiding the potentially misleading trope of 'period-like pain', establishing more effective

anticipatory guidance and, overall, prioritizing the elimination of pain in this routine component of sexual and reproductive healthcare. Further work is needed to unpick the cultural assumptions underpinning pain as an unavoidable element of EMA.

Bridging the relationship between sexual pleasure and contraceptive counseling

Erica Selznick (University of Antwerp), Anneleen De Cuyper (University of Antwerp), Sarah Van de Velde (University of Antwerp)

Abstract

Sexual pleasure is critical to sexual health and wellbeing, deemed a fundamental component of sexual rights by the World Association for Sexual Health.¹ However, sexual pleasure is often neglected in health care provision despite its relevance to an abundance of topics, such as contraception. Many contraceptive methods influence users' pleasure and during contraceptive decision making, users often consider this relationship, initiating, changing, or stopping using a method based on their perceived impact on how a method will influence their own or a partner's sexual pleasure.^{2,3} However, this consideration is often internalized and not communicated with providers, largely due to the stigmatization surrounding this topic. Structural elements further hinder the inclusion of pleasure in contraceptive counseling, as providers are often inadequately trained to discuss this aspect of sexual health with patients.⁴ Additionally, provider-focused recommendations vary widely, as do understandings of the role contraceptive counseling can have in implementing sexual pleasure within healthcare, delaying execution. The lack of pleasure-based approaches in contraceptive counseling can lead to gaps in personalized care and unmet need, as contraceptive choices might not be ideally suited to one's needs or desires and therefore unutilized or discontinued.⁵ This scoping review will address gaps regarding how contraceptive counseling can bridge the relationship between sexual pleasure and contraceptive decision making, developing a stronger consensus through exploring variations in conceptualizations and recommendations.

A scoping review will be conducted, exploring how literature linking sexual pleasure and contraception situates contraceptive counseling. This review of the literature will analyze different approaches connecting these factors, compare structural recommendations aimed towards providers and health systems, and identify gaps in conceptualizations of the relationship between sexual pleasure, contraception, and contraceptive counseling. Complementing the literature, qualitative interviews with experts in sexual health and contraception will be conducted. These interviews will explore how to bridge the connection between contraceptive counseling and sexual pleasure, why recommendations vary widely, and why implementation significantly lags.

This review will assemble a comprehensive understanding of how contraceptive counseling is currently presented within literature linking contraception and sexual pleasure. Findings will demonstrate existing understandings of the topic, from academic and systemic perspectives. This will identify structural variations and agreements in the role contraceptive counseling can take to incorporate sexual pleasure, which can highlight gaps requiring additional research and find points of concurrence that can be built upon through protocol development. Further, this review will identify variation across provider-based recommendations regarding implementing sexual pleasure into contraceptive counseling. This will additionally recognize possible points of contention requiring stronger consensus to better inform guidelines and policy, as well as recognize agreed upon points that require further reinforcing to better facilitate implementation.

Synthesizing research regarding how contraceptive counseling can incorporate pleasure-based approaches and bridge the relationship between sexual pleasure and contraception will develop a stronger consensus that can provide a more developed, concrete foundation for future research addressing the topic. Findings will inform policy recommendations and protocol developments aimed towards providers and health systems to better incorporate sexual pleasure into contraceptive counseling. This will address a gap in sexual and reproductive health care, as pleasure-based approaches are increasingly recognized as critical to health and wellbeing, yet execution lags significantly. Better informed protocols resulting from these findings can effectively implement

sexual pleasure within contraceptive counseling to enable more personalized, informed contraceptive decision making.

Intersectionality in health as a normative imperative: The case of abortion in Northern Ireland

Peter Keogh (The Open University), Naomi Connor (Alliance for Choice)

Introduction

Deployments of the concept of intersectionality within medical sociology tend to focus on the ways in which multiple and overlapping individual and group experiences/identities interact with structural inequalities to mediate health outcomes and inform the health challenges people face. Intersectionality is often seen as a way of understanding or interpreting health experiences and differential health outcomes. Thus, intersectionality is frequently deployed as a descriptive or interpretive theory.

In contrast, within political science and socio-legal disciplines, intersectionality frequently has a normative dimension that entails framing and responding to a political or social challenge in an intersectional manner. This normative dimension is more in keeping with intersectionality's roots in Black feminist theory in that it implies an overtly political focus, an inherent critique of power and a set of engagements to bring about social and political change (Hajer Al-Faham & Davis, 2019; Ciccio & Roggeband, 2021).

In health, we are seeing the emergence of this normative aspect of intersectionality with calls to 'take an intersectional approach' in the development of health policies and the organization of health services. However, we know little about what taking an intersectional approach to the development of health policy and health provision looks like in practice. In this presentation, we will use the example of abortion in Northern Ireland to explore what is entailed in adopting this distinctively normative understanding of intersectionality with reference to a health issue.

Approach

We (the authors) are a sociologist of health and illness and a leading reproductive health activist. We are engaged in an ongoing knowledge exchange partnership the output of which is an online learning hub aimed at reproductive health actors and activists globally. The learning hub draws on unique expertise and insights developed by health actors and activists in Northern Ireland during the campaign to decriminalize abortion in 2019 and ongoing effort to develop and deliver abortion services following decriminalization. We will use the materials and insights we have gathered in generating this online learning hub to discuss the case of abortion in Northern Ireland as an example of a health issue, framed as and responded to, in an intersectional way.

Insights and Findings

The campaign to decriminalize abortion in Northern Ireland was multi-sectoral mobilizing a broad coalition of civil society actors and professional disciplines including health practitioners and health policy actors. Abortion was and continues to be framed as an intersectional health issue [Bloomer & Campbell, 2022]: abortion access and reproductive health outcomes are mediated by social and structural inequality and securing abortion provision entails engagement with complex political tensions expressed through intersectional identities and group belongings along political, religious-cultural and economic lines.

Taking an intersectional approach to securing abortion decriminalization and provision has obliged reproductive health actors and activists to occupy a range of disciplinary spaces including engaging proactively in legal, political, cultural/media/arts arenas in increasingly sophisticated ways. Moreover, it has also entailed the establishment and maintenance of enduring solidarities across various social and health issues. For example, reproductive health actors and activists in Northern Ireland have formed meaningful solidarities with LGBT+ movements, refugee organizations, trades unions, faith groups and Irish language organizations all of which have been essential to securing abortion provision.

Discussion

The experience of reproductive health actors and activists around the issue of abortion in Northern Ireland tells us much about the commitments, entanglements and solidarities associated with framing and responding to a health issue in an intersectional way. Although abortion as a health issue has clear political and legal dimensions, working in health in the normative sense of intersectionality implied by political science and socio-legal disciplines is likely to surface underlying political valences in health issues more generally and may have the potential to (re)articulate a broader politics of health.

We will conclude by proposing an expansion of the concept of intersectionality as it is currently understood in health discourses. In addition to our current understanding of multiple and overlapping individual and group experiences/identities, two other 'intersections' are suggested. The first is the intersection between health and other disciplines/discourses (primarily legal and political) and the second is the intersection between the health issue in question and other non-health social and political issues that are closely related. Working at these different intersections requires health actors and activists to develop a wide range of competencies and knowledges across disciplines as well as establishing enduring solidarities with others outside of the health realm.

Social Inequalities in Healthcare Use, Thematic Session – Chair: Heta Moustgaard – Room K.201

The maternal healthcare experiences of women seeking sanctuary in Wales: A linked data study

Alix Bukkfalvi-Cadotte (Swansea University Medical School), Helen Snooks (Swansea University Medical School), Amy Brown (Swansea University School of Health and Social Care), Khanom Ashra (Swansea University Medical School)

Introduction

Research has shown that migrant populations can face obstacles in accessing high quality health care, including communication and cultural barriers, as well as potential discrimination from care providers. In maternity care specifically, migrant women's experiences of care can conflict with cultural beliefs and practices related to childbirth and family, and they may receive inadequate care for particular obstetric issues, such as female genital mutilation. Among migrant populations, refugees and asylum seekers have particularly complex health needs linked to experiences in the country of origin, the journey to the host country, and socioeconomic status in the host country. While extensive research on migration health in the UK has been conducted in recent years, few studies have focused specifically on refugees and asylum seekers' maternity care experiences. Due to limited access to disaggregated data concerning refugees and asylum seekers in the UK, no large-scale quantitative studies examine their experiences of maternity care.

The aim of this study is to describe the population of maternity care service users seeking sanctuary in Wales and to determine whether their use of maternity care services and perinatal health outcomes differ from those of non-refugee individuals.

Methodology

Working with SAIL Databank, I will link six anonymized datasets and extract data regarding the patient characteristics, clinical interventions performed during pregnancy, labor, and childbirth, as well as perinatal health outcomes for all women who gave birth in Wales since 2014. Using a novel method, I will identify individuals recorded as refugees or asylum seekers in General Practitioner (GP) records via the Welsh Longitudinal General Practice Dataset. I will calculate summary statistics for the demographic characteristics of the study group identified through this method.

I will explore the available data related to maternity care service use and perinatal health outcomes (e.g. induction of labor, epidural use, low birth weight) to establish whether there are disparities between refugees and asylum seekers and non-refugee individuals. I will calculate summary statistics for maternal health-related data, compare results between the study group and a non-refugee comparator group and perform chi-squared tests to identify any statistically significant differences between groups. Where the completeness and quality of data allow for it, I will calculate odds ratios comparing binary maternal and child health outcomes in the study population and among non-refugee individuals and I will conduct logistic regression analyses to control for known potential covariates associated with adverse perinatal outcomes (such as maternal age, parity, smoking, maternal weight).

Results

I will report on the availability of GP data regarding refugee or asylum seeker status in the Welsh Longitudinal General Practice Dataset, the benefits and the limitations of using this data to identify refugee and asylum seeker populations.

The anticipated results of the data linkage will include preliminary count and percentage data for patient characteristics, maternity care service use and perinatal health outcome variables, such as: Maternal age; Type of maternity care received; Timing of initial assessment; Induction of labor; Epidural use; Episiotomy; Low birth weight; and Apgar score for refugees and asylum seekers as compared to non-refugee individuals. If the quality of the data is sufficient, it will also include odds ratios comparing binary maternal and child health outcomes in the study population and among non-refugee individuals.

I will present and discuss the statistical significance of the results, highlighting any significant disparities between the groups. I will identify any specific aspect of maternity care service use and outcomes that may vary based on refugee or asylum seeker status, providing insights into the relationship between migration and health.

Conclusion

The proposed data linkage study will inform policy and practice regarding the provision of maternity care to women seeking sanctuary in Wales and the reduction of health inequities. Additionally, this study will demonstrate the use of a novel method to identify refugees and asylum seekers, a population that is often invisible in large scale datasets. It highlights the potential of dataset linkage and secondary data analysis to improve the monitoring of population health status.

Maternal delays and unfavorable newborn outcomes among skilled deliveries in public hospitals of Hadiya Zone, Southern Ethiopia: A case– control study

Dawit Erjino (Wachemo University), Abera Beyamo Mekiso, Lonsako Abute Woiloro, Tegegn Tadesse Arficho, Aregash Mecha Watumo, Nuradin Abusha Katiso, Tadesse Lelago Ermolo

Object

We assessed maternal delays and unfavorable newborn outcomes among skilled deliveries in public hospitals of Hadiya Zone, Southern Ethiopia using ‘the three maternal delays’ framework.

Methods

A case–control study was conducted. Setting: Public hospitals in Hadiya Zone, southern Ethiopia. Sample of 57 cases and 121 controls participated from 4 September 2019 to 30 October 2019. Consecutive dead newborns at discharge or admitted newborns for more 24 hours after delivery were selected as cases. Two consecutive controls were selected from none cases discharged within 24 hours of skilled delivery.

Results

Total of 57 cases and 121 controls participated with 97.3% response rate. Forty-eight (84.2%), 46 (80.7%) and 51

(89.5%) of cases had first, second and third maternal delay, respectively. Eighty-six (71.1%), 18 (14.9%) and 69 (53.7%) of controls had first, second and third maternal delay, respectively. Cases with second maternal delay were 23.9 times more likely to have unfavorable newborn outcome when compared with controls. The first and third delays and wealth index were not significantly associated with newborn outcome in this study.

Conclusions

First, second and third maternal delays were higher in cases than controls. 'Delay in reaching health facility' was determinant for unfavorable newborn outcome in this study. However, 'delay in decision-making to seek care' and 'delay in receiving care' were not significantly associated with new born outcome. Government should work to improve laboring mother transportation.

Sociodemographic inequalities and access to habilitation-centers among Norwegian children with Downs syndrome and cerebral palsy

Jon Erik Finnvoll (Oslo Metropolitan University), Therese Dokken (Oslo Metropolitan University)

Introduction

The purpose of this study is to identify factors that affect children and youth's chances of being admitted to stays at habilitation-centers. We analyze characteristics of the child/youth and the family, as well as institutional and geographical aspects in a population with Downs syndrome and Cerebral palsy.

Norwegian (re)habilitation-centers include highly qualified staff and inter-disciplinary expertise. Previous research has documented positive outcomes in the daily lives of patients following stays in (re)habilitation centers (Preede, Saebu et al. 2015). Most (re)habilitation-centers are private, but exist within the institutional structure of the Norwegian welfare state as a public health service delivery (Schönfelder and Bliksvær 2011). Stays at centers are free of charge. Families can apply for stays on behalf of their children, but only through a referral system. A referral can be made in two ways: GPs and privately practising specialists first write a referral to a regional coordinating unit. If accepted, the referral will be forwarded to the habilitation-centre of choice for final decision. In the second procedure, specialists at hospitals refer directly to the centers. The referral must contain information about how the diagnosis and its related problems affect the child's daily functioning and what kind of measures have been taken locally in the municipality. The referral must also include a clear objective or motivation for the stay.

Access to habilitation-stays can be conceived of as a process of local justice in which the gatekeepers and professionals apply various criteria in their decisions. In our case, we use a number of characteristics regarding the health situation of the children in our sample, including severity of condition, the presence of co-morbidity, level of need for daily assistance and level of ability for oral speech. Variations in these aspects may have different consequences for the physician's decisions to refer. Regarding institutional context, a Swedish study found that children with developmental disabilities who were integrated in mainstream classes utilized significantly fewer types of habilitation-services compared to children in special classes (Olsson, Elgmark Andersson et al. 2017).

Children will also have different sources of regular health care. Some consider specialists at hospitals as their regular physician, other use a GP or a privately practicing specialist as their regular doctor. The level of specialization may have implications for access to habilitation-stays. There is no mechanism in place that allocate the use of resources in habilitation-centers to the children and youths in the target groups with the highest need or the best potential to benefit from stays. Knowledge about the existence of the centers may not be equally distributed in the target population. Aspects of the families' social network such as the presence of a physician can have an impact, as can membership in relevant user-organizations. Another possible source of information is participation in social-media groups organized by user-organizations. Family characteristics such as parental educational attainment and immigrant background may also influence access, whether as a direct effect or as a mediation factor for other attributes of families or their institutional context.

Methodology

Based on interviews with parents, we designed a questionnaire and conducted a survey in the autumn of 2023. The population of investigation consisted of a nationally representative population that had received basic- and/or attendance benefit because their child had Downs syndrome or Cerebral palsy (N=1943). A total of 769 parents returned an online questionnaire. The net sample was merged with various registers by Statistics Norway, and further characteristics about the children, their parents and their place of residence was added to the dataset. We applied multivariate regression in our analyses.

Results

A total of 36 percent had one or more stays at a center. One in four stated that they were not aware of the possibility to apply for a stay. About 20 percent responded that they did not need a stay. Relatively few had their applications turned down. Children with Cerebral palsy was twice as likely to be admitted compared to children with Downs syndrome. Children with limited ability to verbal communication were considerably less probable to be admitted. A marked difference could be observed between children that was fully integrated in ordinary classroom education and children in segregated settings. Unlike the experience from Sweden, it was more common for children in integrated settings to be admitted. Another clear difference was between children referred from a specialist at a hospital and children referred by a GP. Children referred from a specialist was more often admitted. Furthermore, we see that children of parents who were active on social media had a greater chance of being admitted, the same applied if the mother was employed.

Conclusion

Habilitation-centers aim to promote active participation in society. Our results suggest that the least socially integrated children (in school, with limited verbal communication skills) are among groups with the least chances of being admitted.

Mandatory separation of mothers from newborns in UK prisons: Findings from the Lost Mothers Project.

Laura Jane Abbott (University of Hertfordshire), Natalie Avlonitis (University of Hertfordshire), Kate Chivers (Birth Companions)

Background

Exploring the intricate intersection of maternal experiences within the UK prison system, this presentation addresses the gaps in understanding and support for pregnant women and new mothers in carceral settings. While precise statistics are lacking, estimates suggest that 6-7% of the female prison population experiences pregnancy, with approximately 100 babies born to incarcerated women each year (Abbott, 2018).

Qualitative research sheds light on the emotional toll of mandatory separation from newborns, revealing a profound sense of loss among affected imprisoned women (Abbott et al. 2021). The ensuing trauma contributes to heightened adverse mental health outcomes (O'Malley and Baldwin, 2019). Additionally, pregnant women in prison grapple with isolation and fear, facing elevated risks of miscarriage and pregnancy complications (Davies, Hutchings, and Keeble, 2022).

The Lost Mothers study pioneers a collaborative approach, intertwining the perspectives of social work, health visiting, midwifery, and criminal justice. By centering the experiences of formerly incarcerated women, our research aims to:

- Illuminate the multifaceted effects of mandatory separation on imprisoned women and their infants.
- Foster interdisciplinary collaboration among professionals in health, social care, and prisons to co-create guidance supporting women in these circumstances.

- Advance an empirically grounded conceptual framework contributing to the sociology of loss and grief, with a specific focus on the mandatory separation of babies from mothers in prison. In doing so, we strive for a more inclusive and intersectional approach to maternal health within carceral environments.

Methodology

Employing a qualitative research paradigm, this study adopts an in-depth approach that integrates an extensive literature review with thematic analysis of narratives derived from semi-structured interviews. Focused on six underutilized Mother and Baby Units (MBUs) situated within 12 women's prisons across the UK, the research seeks to elucidate the nuanced experiences of women undergoing mandatory separation from their newborns. The methodological rigor applied in this qualitative inquiry is designed to reveal the intricate dimensions of maternal health disparities within the carceral context.

Qualitative Interviews: In-depth qualitative interviews provide a comprehensive understanding of the lived experiences of incarcerated mothers. Participants share their perspectives on the challenges and emotional toll associated with mandatory separation from their newborns. This narrative-driven approach allows for the exploration of individual stories, providing insights into coping mechanisms, resilience, and the unique aspects of maternal health disparities within the prison setting.

Observations of Mother and Baby Boards: The study incorporates direct observations of the processes involved in Mother and Baby Boards within the identified Mother and Baby Units. This observational component aims to elucidate the decision-making mechanisms governing the separation of mothers from their infants. The analysis focuses on identifying patterns, protocols, and potential gaps in the decision-making processes, contributing to a comprehensive understanding of the institutional dynamics shaping maternal health outcomes.

Thematic Analysis: Utilizing thematic analysis as a robust methodological framework, this study delves into the rich narratives derived from qualitative interviews and observational data. Preliminary themes have started to emerge, capturing the diverse and often complex experiences of incarcerated mothers undergoing mandatory separation from their newborns. Themes are identified through systematic coding, enabling a nuanced exploration of the emotional, psychological, and social dimensions of maternal health disparities within the prison context.

Identification of Gaps: Through a meticulous examination of qualitative data, observational findings, and existing literature, this study seeks to identify gaps in the current system. These gaps may pertain to policy inadequacies, disparities in decision-making, or systemic challenges that contribute to the complex landscape of maternal health within the prison environment. The identification of these gaps is critical for proposing informed recommendations that can address the root causes of maternal health disparities and guide the development of inclusive policies and practices.

In essence, the multi-faceted approach of this study, incorporating thematic analysis, qualitative interviews, and direct observations, allows for a holistic exploration of the intersectional nature of maternal health disparities in the context of mandatory separation in Mother and Baby Units within UK women's prisons.

Conclusion

This pioneering qualitative project transcends disciplinary boundaries, encompassing social work, health visiting, midwifery, and criminal justice, with a deliberate focus on centering the experiences of incarcerated women. The forthcoming recommendations are poised to contribute significantly to informing policies and practices, offering valuable qualitative insights that will enrich academic research in sociology of health and illness, criminology, midwifery, health visiting, and social work. The holistic approach adopted in this study aligns seamlessly with the principles of intersectionality and inclusion, aiming to address health disparities through a multidimensional lens.

Social inequalities in abortion health care

Marlyse Debergh (University of Amsterdam)

Abstract

How are contemporary social inequalities impacting the access to abortion care in Europe?

Based on an ethnography conducted in the Netherlands and in Switzerland, this talk aims at addressing this question by providing concrete empirical data and qualitative analysis. The data include 19 interviews conducted with sexual health professionals (gynecologists, abortion doctors, nurses, midwives and sexual health counsellors), feminists from three pro-choice collectives, and sexual health experts, as well as from a selection of public health documents. The data are analyzed with a qualitative thematic analysis with the software Atlas.TI.

Based on a reproductive justice theoretical framework, the results of this research show that gender, race and class dynamics prevent women from accessing abortion care in Europe. Echoing previous research (De Zordo et al., 2021, 2023; Garnsey et al., 2021), this is mainly the case for women who come from Poland where abortion is almost entirely banned, but also from countries where abortion is legal, such as Switzerland. Furthermore, this communication shows how inequalities impact “abortion work” (Mathieu & Thizy, 2023) provided by health professionals and feminist activists. Finally, my communication opens up to a discussion on how this case study on abortion can help us to understand various intersectional inequalities in health care.

Socioeconomic Status and Health, Regular Session - Chair: Malgorzata Mikucka – Room K.202

The socioeconomic consequences of loneliness: Evidence from a nationally representative longitudinal study of young adults

Bridget Bryan (King’s College London), Louise Arseneault (King’s College London), Timothy Matthews (University of Greenwich), Katherine Thompson (Purdue University)

Background

The health and economic consequences of loneliness have gained increasing attention from the public and policymakers in recent years. As loneliness has been identified as a risk factor for mental health problems, poor physical health and mortality, much of this concern has focused on the indirect economic costs arising from healthcare expenditure associated with loneliness. However, loneliness may also exert an economic burden through a direct pathway from loneliness to socioeconomic outcomes, which may, in turn, impact health. Much of the research on loneliness to date has focused on employment status which may not fully capture socioeconomic position and has relied on cross-sectional data, leaving questions around the robustness of the association and reverse causation.

Objectives

The present study used longitudinal data to test prospective associations between loneliness and multiple indicators of social position in young adulthood, specifically, whether participants who were lonelier at age 12 were more likely to be out of employment, education and training (NEET) and lower on employability and subjective social status as young adults.

Methods

The data were drawn from the Environmental Risk (E-Risk) Longitudinal Twin Study, a birth cohort of 2,232 individuals born in England and Wales during 1994–1995. Loneliness and subjective social status were measured

at ages 12, 18 and 26. Employability and NEET status were assessed at age 18. Mental health was indicated by depression and anxiety symptoms at age 12 and 18. Prospective and cross-sectional associations between loneliness and socioeconomic position were tested using a series of logistic and linear regression models adjusting for mental health difficulties at age 12 and 18. The robustness the association between loneliness and subjective social status was tested using a sibling-control method to compare the reports of twin pairs living in the same household. The direction of the association between loneliness and social status across adolescence and young adulthood was assessed using the random-intercept cross-lagged panel model.

Results

Findings indicate that greater loneliness at age 12 was prospectively associated with reduced employability and lower social status in young adulthood. The association between loneliness and lower social status in young adulthood was robust when controlling for a range of confounders using a sibling-control design. Results also indicate that loneliness is unidirectionally associated with reduced subjective social status across adolescence and young adulthood.

Conclusions

Overall, our findings indicate that loneliness in early adolescence and young adulthood has consequences for individuals' employability and subjective social status, which may have direct costs to the economy resulting from reduced labor market performance. In light of the link between subjective social status and mental and physical health problems, the impact of loneliness on social status may also be an additional pathway through which loneliness impacts health.

Educational inequalities in COVID-19 mortality: A global systematic review and meta-analysis

Insa Backhaus (Norwegian University of Science and Technology), Claire Henson (Institute for Health Metrics and Evaluation United States), Hanno Hoven (Centre for Global Health Inequalities Research (CHAIN), Norwegian University of Science and Technology), Emmanuela Gakidou (Institute for Health Metrics and Evaluation United States), Terje Andreas Eikemo (Centre for Global Health Inequalities Research (CHAIN), Norwegian University of Science and Technology), Mirza Balaj (Centre for Global Health Inequalities Research (CHAIN), Norwegian University of Science and Technology)

Background

Education is an important determinant of health, and every additional year of schooling reduces the all-cause mortality risk. However, the magnitude of education on specific causes of death – such as COVID-19– is currently unknown. We critically reviewed and analyzed available evidence to quantify the impact of education on COVID-19 mortality risk.

Methods

We performed a systematic review and meta-analysis of the effect of education on COVID-19 adult mortality. We searched PubMed, Web of Science, Scopus, EMBASE, Global Health (CAB), EconLit, and Sociology Source Ultimate databases in August 2020 to identify studies investigating the association between education and COVID-19 mortality. Two reviewers independently screened titles and abstract, full texts and extracted data. We applied mixed-effects meta-regression models to address heterogeneity in referent and exposure measures among studies, and to adjust for study-level covariates. This study was registered with PROSPERO (ID CRD42020183923).

Findings

The initial literature search yielded 40.108 articles. After removal of duplicates and the exclusion of studies that did not fit the inclusion criteria during the title and abstract screening and full text assessment, 28 articles were identified as eligible for data extraction. The analysis shows a dose-response relationship between education and adult COVID-19 mortality. Specifically, after 6 years of education we can observe a risk reduction by 23%

compared to 0 years of education. This further improved and when achieving 12 years of education the mortality risk was reduced by 39.8% and even by 53.3% when achieving 18 years of education compared to 0 years of education.

Conclusion

Our study adds to the compelling body evidence showing the beneficial effect of education for adult health. Ensuring access to education and increasing years of schooling can be an important measure to improve overall health and well-being.

Unravelling connections: Family social capital, socio-economic status, and health literacy among primary school pupils in Poland.

Maria Świątkiewicz-Mośny (Jagiellonian University), Magdalena Ślusarczyk (Jagiellonian University), Natalia Ożegalska-Łukasik (Jagiellonian University), Małgorzata Bała (Jagiellonian University), Anna Prokop-Dorner (Jagiellonian University), Aleksandra Piłat-Kobla (Jagiellonian University)

Introduction

Health literacy is recognized not only as an individual characteristic or a factor contributing to suboptimal health outcomes, but also as a favorable trait or attribute associated with families, communities, and organizations engaged in providing health and social services (Batterham et al., 2016). Regarded as a valuable quality, health literacy, especially critical thinking about health, provides a pathway for enabling individuals and communities to enhance their influence over their well-being (Aljassim & Ostini, 2020; Nutbeam, 2008). Our study aimed to investigate the relationship between family social capital and the level of health literacy among primary school pupils' socio-economic status.

Methodology

Our research was based on the survey undertaken in Poland in 2023, involving a representative sample of 2242 pupils aged 11-15. We employed the adapted and validated questionnaire using the Claim Evaluation Tool developed by a Norwegian team as part of the Informed Health Choices (IHC) project (Austvoll-Dahlgren et al., 2017) which was validated in various countries such as China (Wang, 2019), Mexico (Gaxiola 2018), Croatia (Aranza et al., 2021), and Uganda (Semakula et al, 2017), the study focused on evaluating health literacy skills. To enhance the examination of socioeconomic factors, questions about socioeconomic capitals were incorporated into the IHC questionnaire. As the research was conducted among children using an auditorium survey technique, investigating socio-economic capital posed a challenge. By recognizing the potential unreliability of inquiring about income or possessions, as children may lack this information, alternative indicators were explored. As such, inquiries were directed towards whether the child possesses their room (a housing indicator), the educational background of the parents (a tertiary education indicator), how holidays are spent (an economic indicator), and the participation in extra-curricular activities by the child (an economic and cultural capital indicator).

Results

The study, conducted from September to November 2023, is currently undergoing analytical processing. Initial findings indicate a strong correlation between the IHC score and key socioeconomic capital indicators, encompassing parental educational attainment, ownership of individual living space, the ability to afford holidays, and participation in extra-curricular activities. These findings suggest that, as established in existing research, socioeconomic status not only shapes health-related choices and access to adequate healthcare but also plays a pivotal role in the development of coping mechanisms for health claims. This becomes particularly relevant in the era of an infodemic, emphasizing the importance of understanding and managing health information.

Furthermore, gender emerges as an additional influential factor, highlighting the potential necessity for reconsideration of differentiated approaches in health education methods. This insight underscores the need for nuanced and targeted strategies to address diverse socio-economic backgrounds and gender-specific considerations in promoting health literacy.

Conclusions

We conclude that health disparities stem from social status differences, notably lower education and income. Health literacy is essential for obtaining, understanding, and utilizing medical information, and it plays a significant role in shaping the health of both individuals and society. This study highlights the need to grasp the interaction between health literacy and socioeconomic factors in shaping health outcomes.

Social class or social foreground: Understanding the link between adult children's education and parent mortality

Shawn Bauldry (Purdue University), Joseph Wolfe (University of Alabama at Birmingham)

Introduction

A growing body of research documents a relationship between adult children's education and parent health, an inversion of the much more frequently studied transmission of resources from parents to their children ((Fraser et al. 2022; Peng et al. 2019; J. D. Wolfe et al. 2018; J. Wolfe et al. 2018)). In this study we examine the extent to which social class as indicated by wealth both confounders and moderates the link between adult children's education and parent mortality.

Methodology

We draw on the 2000 to 2020 waves of the Health and Retirement Study (HRS), a nationally representative sample of adults ages 50 and older in the United States, for our analysis. The HRS includes a census of the children of the respondents beginning in 2000 that documents levels of education as well as other characteristics. We construct a measure of adult children's education based on the highest level of education among any of the parents' children. In addition, the HRS includes detailed information on levels of wealth of respondents and has been linked with National Death Records to document mortality. We use Cox proportional hazards models to establish net associations and parametric survival models to examine median ages of death for different subpopulations to assess the moderating effect of wealth.

Results

Preliminary results indicate that adult children's education maintains an association with parent mortality after adjusting for parent wealth (and a number of additional parent and adult children characteristics). For instance, parents with at least one adult child with a college degree have a 21 percent lower hazard of mortality than parents with no children with at least a college degree. In addition, we find evidence that wealth interacts with adult children's education such that having more educated children has less of an association with parent mortality for respondents with higher levels of wealth.

Conclusion

Incorporating wealth into analyses of adult children's education and parent mortality provides additional insight into multigenerational process linking socioeconomic position and health.

Labor, Work, Health and Inclusion, Thematic Session – Chair: Jennifer Remnant – Room K.203

Informal employment as a social determinant of health: A framework and research agenda accounting for heterogeneity and context

Amanda Aronsson (Norwegian University of Technology and Science), Tim Huijts (Maastricht University)

Introduction

Informal employment (IE), that is employment that is not covered by national labor legislation or employment-based social protection, is the most common type of employment globally. Yet despite work being a known Social Determinant of Health (SDH), the links between IE and health are inadequately understood. Research with a comparative approach and attention to pathways is needed for a more comprehensive understanding. However, the existing body of quantitative evidence has produced inconclusive results and attempts to synthesize and explain these findings are complicated by the heterogeneity of IE and by the lack of theoretical frameworks specifically focused on informality. Still, given that most workers globally are informally employed, there is an urgency to consider greater nuances of the health consequences of IE and to identify groups that are particularly vulnerable to informality.

Aim

With the overarching aim of facilitating research to advance the understanding of IE as a SDH and its links to health inequalities, the objectives of this paper are to critically review the main limitations of existing research; to develop a conceptual framework that overcomes these challenges and to provide a research agenda for future research.

Existing limitations and conceptual Framework. This paper initially reviews the current state of research and identifies notable limitations in how IE can be understood as a SDH. Specifically, the existing research lacks attention to pathways and provides insufficient explanations for the heterogeneity of effects across different settings as well as social groups. To address these limitations, we present a conceptual framework that emphasizes the importance of accounting for context. The ambiguity around the term 'context' can challenge attempts to integrate contextual factors into the analysis, especially in comparative research. Therefore, we also present a strategy for how context can be operationalized at the macro- and meso-level in a way that is relevant for IE. By bringing context into the analysis, the framework allows for IE to be a heterogeneous phenomenon, thereby enabling comparative research. Furthermore, a context-centered framework encourages attention to pathways, and specifically the interplay between IE and factors located at micro-, meso- and macro-level. By considering the moderating role of contextual factors in the relationship between IE and health, such as by exploring how contextual factors interact with individual-level factors like age or gender and IE, we can better compare and explain variations in health as a consequence of IE.

Research Agenda and implications. From this framework, we propose a research agenda at the end of the paper. Here, we identify priorities and pressing questions for future research. This paper should be a useful conceptual contribution for researchers interested in enhancing the understanding of IE as a SDH and could allow for more nuanced understandings as to when, why and for whom, IE determines ill-health.

Designing inclusive remote and hybrid working to support disabled workers

Calum Carson (Lancaster University), Paula Holland (Lancaster University), Rebecca Florisson (Work Foundation; Lancaster University), Alison Collins (Manchester Metropolitan University), Jacqueline Winstanley (Lancaster University)

Abstract

The COVID-19 pandemic instigated widespread change to working practices, both within the UK and across the world: over three years on, remote and hybrid working is still available to many desk-based workers and job-seekers, despite a well-publicized employer pushback to “*get people back to the office*” as the peak of the pandemic has ended. One-fifth of working-age people in the UK are currently categorized as disabled, yet their working preferences, and their experiences of remote or hybrid working both during the pandemic and across the post-pandemic landscape, remain largely unexplored. This project seeks to rectify this by exploring disabled workers’ experiences of remote and hybrid working, alongside a focus on employer and policymaker perspectives within this field, and to identify how best to make these new and increasingly popular models of work more inclusive for disabled workers across the UK.

The disability employment gap in the UK currently stands at 29.8 percentage points and is largely driven by organizational inflexibility and non-inclusive workplace policies and practice. Remote working offers flexibility to schedule work around fatigue or pain, and to reallocate energy used for commuting, yet prior to the pandemic employers were often reluctant to allow disabled staff to work remotely, even as a reasonable adjustment. Requests for disabled people to work within a hybrid model have also routinely been rejected by employers.

Our previous research within this area of inquiry found that remote working was positive for disabled workers’ physical and mental health, productivity and employment (Taylor et al, 2022), with remote working particularly valued by disabled women, younger disabled people, people with multiple impairments and disabled carers. This larger-scale mixed-methods study, funded by the Nuffield Foundation, builds on this, exploring how remote and hybrid working can be designed to be inclusive of disabled workers’ needs and preferences to promote their job retention, recruitment and progression.

Underpinned by the Job Demands-Resources model and an intersectional framework, we explore through a national survey and in-depth interviews disabled workers’ perspectives on the benefits and challenges of remote and hybrid working in relation to their employment, health/wellbeing, productivity and work-life balance, and factors they perceive as enabling inclusive remote/hybrid working. Through organizational case studies, we will also identify whether and how employers are implementing inclusive remote/hybrid working, and through discussions with policymakers how the UK policy apparatus can be leveraged to better support more inclusive models of remote and hybrid work within the labor market.

The central focus of this conference paper will be on exploring emergent findings from the first stage of the fieldwork for this project, centered upon disabled workers’ own experiences. Utilizing data from a survey of over 1,500 UK-based workers and 50 in-depth interviews conducted over the course of the past year, it will explore both their thoughts on their own remote and hybrid working experiences to date as well as their recommendations for how employers and policymakers can structure these models of work in the future to make them more inclusive of disabled workers’ needs within the workplace. These findings will inform the next stage of the project, focused upon exploring issues of inclusivity within the remote and hybrid working agenda from the employer perspective.

Working conditions, self-perceived health and use of health services among migrant agricultural workers in Spain

Erica Briones-Vozmediano (University of Lleida)

Background

In Spain, it is usual to hire seasonal migrant agricultural workers. The duration of the contracts obliges migrant seasonal agricultural workers to move between different agricultural regions and seasons for several months, making it difficult for them to settle, with direct repercussions on migratory status, access to decent work, housing resources, and health care.

Objective

To describe the working conditions, self-perceived health, and use of health services of agricultural workers of African origin in Spain

Methods

Cross-sectional, multicenter study. A 43-question questionnaire was designed based on the Spanish National Health Survey, the Spanish National Survey of Living Conditions, and a previous experience of a project on the occupational health of migrants. Data collection occurred in 2022 in four Spanish regions with a high concentration of migrant agricultural workers (Huelva, Almería, Lleida, and La Rioja). Descriptive statistics were calculated.

Results

623 agricultural workers (65% Men, 34% Women) from 21 countries on the African continent were surveyed: 62% Maghreb and 38% sub-Saharan. 40% of the men and 88% of the women were Moroccan. The mean age was 36.6 years (17-75). 53% of the sample had no education. 77% had a residence time in Spain of more than two years. 38% of the men vs. 16% of the women did not have a residence permit.

Working conditions: 46% of the sample lifted, carried, or pushed heavy objects of more than 20 kg or more manually at least 10 times a day, and 14% (19%M, 5%W) used chemicals, flammable liquids, and gases. 29% (35%M, 17%W) had received information or courses on occupational hazards from their employer or employer's company. 48% (61%M, 21%W) of the sample did not have the necessary protection, such as gloves, masks, hard hats, etc., at their workplace, and 54% (50%M, 61%W) of the sample did not know their rights and responsibilities about their health and safety at work.

Health status: 74% (82%M, 65%W) perceived their health as "Very good" or "Good". Smoking (45%M, 2%W) and alcohol consumption were higher among men (22%M, 2%W). 69% of workers reported feeling not at all limited in their usual activities in the last six months (75%M, 61%W). 29% reported musculoskeletal pain (21%M, 46%W), 18% fatigue (14% M, 29%W), 17% nervous system problems (12%M, 29%W), and 12% digestive system and oral problems (15%M, 8%W). 11% reported mental health problems (9%M, 15%W). 11% suffered accidents at work, home, or leisure (11%M, 9%W). Frequency of medication use in the last 6 months prescribed by a physician was 45% (38M, 60% W), non-prescribed medication use was 29% (27%M, 35%W), and discontinuation of medication treatment due to lack of income was 28% (27%M, 31%W).

Access to healthcare: 88% of the men and 94% of the women had a health insurance card. 93% of the sample reported receiving health care in a public health center or hospital. However, 17% of the sample had never used the Spanish healthcare system (14%M, 24%W). The reason for the last consultation received in Spain was due to a "Diagnosis of an illness or health problem" in 27% (30%W, 23%M) or a "Medical check-up" in 23% (24%W, 23%M). 35% (32%W, 42%M) had had a blood test., 21% (19%W, 26%M) had a urine test, 97% had never had a fecal occult blood test, and 97% of the women had never had a mammography test. Only 8% of the women had had a cytology test. 19% (18%M, 23%M) felt excluded from receiving health care in Spain. 45% took medicines prescribed by a doctor in the last 6 months (38%M, 60%W), while 29% took non-prescribed medication (27%M, 35%W). 28% quit a drug treatment due to lack of income (27%M, 31%W).

Conclusions

Women have poorer self-perceived health, suffer more from pain, fatigue, and other health problems, medicate more, and feel more limited to work despite their working conditions seeming to be safer than men's. Men's good self-perceived health corresponds to the "healthy immigrant syndrome" and the conception of health linked to functionality. Men's good self-perceived health checks the "healthy immigrant syndrome" and the conception of functionality-related health. A next planned qualitative exploration will help to better understand gender differences and health seeking behaviors. Health promotion, including preventive work practices, among these essential but vulnerable workers is needed.

Scholarship disabled: Experiences of ableism within Australian higher education

Peta Cook (University of Tasmania), Ryan Thorneycroft (Western Sydney University), Elizabeth Humphrys (University of Technology Sydney), Nicole Asquith (University of Tasmania), Jess Rodgers (University of Tasmania), Sally Anne Yaghi (Private Practice), Ashleigh Foulstone (Private Practice)

Introduction

Federal legislative requirements require Australian universities to apply 'reasonable' adjustments so that disabled undergraduate students can apply, enroll, participate, and be assessed in their studies. This has allowed increasing numbers of disabled undergraduate students to become part of the university community. Nevertheless, disabled undergraduate students still face barriers to equitable education opportunities and experiences.

While there is significant research on disabled students, research on disabled staff in higher education is an emerging topic. The academy seems promising for disabled staff, particularly academics; a workplace that widely espouses to be inclusive, equitable, and welcoming of diversity. Yet disabled university staff continue to face significant social, cultural, and institutional barriers working against their workplace participation. There remains a gap between policy and the workplace experiences of disabled staff in the academy.

Methodology

In 2019, we formed a cross-institutional team of disabled and non-disabled Australian academics that we named "Scholarship Disabled". From the beginning, our desire has been to explore and examine the experiences of disabled professional and academic staff in Australian higher education. After gaining a small grant, we were able to launch our pilot study, which focused on a large, multi-site university within one of Australia's largest capital cities. Survey (n=20) and interview (n=8) data were collected. While the participant numbers are small, our pilot study provides us with greater insight into the issues facing disabled staff in the academy and assists us to refine the study for a larger project. The interview transcripts and open-ended survey questions were manually coded in NVivo and subjected to thematic analysis. We focus here on the qualitative data.

Results

Our participants noted that within the academy, they are meant to be 'ideal' workers—someone who internalizes 'work' as their identity, labors long hours, is constantly available for workplace demands, and is highly productive. However, disabled workers note they are not provided the resources and support to become the ideal worker; an expectation that they find ableist. Disabled staff within higher education report that they are expected to exceed their capacity and to accept the impact on their health and wellbeing, and consistently experience requests for reasonable adjustment denied. Furthermore, by not being an ideal worker, leadership and promotion opportunities are denied to them, and they are often seen as unproductive, inflexible, or lack a willingness to work hard. In the face of such barriers, disabled staff often felt that they needed to overcompensate. The pacing and scheduling of working life in the academy was reported as misaligning with the time it took to do tasks, and this was particularly profound for disabled academics whereby their temporalities are neglected in the rigid metricisation of their productivity and performance.

Conclusion

Disabled workers in the academy consistently face marginalization and are ignored or considered to be 'problematic' when raising their concerns. The neoliberalization of Australian higher education, which has resulted in reduced funding and increased workloads performance expectations, has entrenched these issues. Notably, what disabled staff consistently face are structural problems, with a reluctance of managers to provide suitable working conditions even when these are available. Therefore, disability is seen as an individual problem, and the disabled person as burdensome. This entrenchment of ableism works against claims of the academy being inclusive, equitable, and welcoming diversity. In the face of such difficulties, it is unsurprising that some of

our participants had not disclosed their disability within the workplace, with the fear of what disclosure could mean. Our work reveals the need for an inclusive revolution within higher education.

Healthy work in times of change: A Positive Health approach

Tim Huijts (Maastricht University)

Introduction

Positive Health is a broad conceptualization of health, in which health is seen as people's ability to cope with physical, emotional and social life challenges, and to use self-management as much as possible. This involves more than just people's physical and mental health. Six dimensions are central: bodily functions, mental well-being, meaningfulness, quality of life, participation, and daily functioning. This view of health was developed by Machteld Huber, a Dutch physician who herself became seriously ill and noticed that health is much more than the absence of disease. Positive Health responds to this by focusing on what people can still do. To this end Huber, together with health care providers and patients among others, developed a method to apply Positive Health in practice, and to offer concrete perspectives for action. This method is mainly used in health care practice, for example by general practitioners. By now, Positive Health is widely used by healthcare providers and other stakeholders in healthcare in the Netherlands, such as policy makers, and the concept is rapidly gaining attention internationally.

Research gap: the link between Positive Health and work. Positive Health is already being used for patients and clients, but couldn't it also be applied to employees? This question is increasingly being asked; in healthcare, but also in other sectors. For example, employers are asking whether Positive Health can help employees to stay healthy, call in sick less and drop out less often. This is understandable, given that organizations face several serious challenges. Absenteeism is high, and there are significant personnel shortages, which will only continue to increase in various sectors. Furthermore, the changes that organizations are rapidly facing, such as automation, financial and political instability, and the aftermath of a pandemic, make great demands on the adaptability of employers and employees alike. Almost half of workers in the Netherlands say that additional measures are needed to reduce work pressure and stress. Developments among young people are particularly concerning. As many as a quarter of employees between the ages of 18 and 34 in the Netherlands struggle with burnout complaints. Increasingly, Positive Health is seen as a promising starting point for addressing this, both by employers and by employees. In some organizations, Positive Health is already completely integrated into personnel policy and leadership visions. Many other organizations only offer workshops or short courses. There are still many questions about how Positive Health can be used in an evidence-based way. This is not surprising: although there are manuals for the use of Positive Health in the workplace, largely based on practical experience, there is still almost no research on Positive Health and work. The main challenge is that Positive Health certainly does not work exactly the same in the workplace as it does in healthcare practice.

Research agenda: a new co-creation program on Positive Health at Work. In this paper, I present a research agenda for a co-creation program around Positive Health at Work, in which we do this together with organizations. In this program, we will focus on answering four questions. Firstly, under what circumstances can Positive Health be implemented effectively (e.g., what is the role of the organizational structure and culture)? Secondly, how does the implementation of Positive Health take shape exactly (e.g., are people from all layers in the organization involved, and in which ways)? Thirdly, what does it work for (e.g., improving health, but also talent development and adaptability)? And fourthly, for whom does it work (e.g., do people with a disability also experience fewer barriers in organizations that work with Positive Health)? To answer these questions, we perform context analyzes, we evaluate the approach in organizations that already work with Positive Health, we ensure further development of the approach, and we advise organizations that do not yet work with Positive Health in the evidence-based design of a new approach. We use a combination of quantitative and qualitative research methods from different scientific disciplines. We draw on existing research on health, work and resilience, and on different theoretical traditions, such as the capability approach, the job demands-resources model, and the complex systems perspective. By involving more and more different organizations in our

research, we can make increasingly concrete recommendations in the process. Ultimately, this will also help us learn what core elements are really needed to successfully deploy Positive Health in the workplace.

4 July: 10:20 – 11:20

Keynote: Charles Agyemang – Room K.001

Cardiovascular disease burden in migrant populations in Europe: Lessons from the RODAM study.

Prof. Charles Agyemang's research focuses on ethnic inequalities in health with a major focus on cardiovascular diseases; and NCDs in low- and middle-income countries. In particular, he focuses on gaining insights into how migration and the contexts in which migrants and ethnic minority groups live and work shape their health, with the ultimate aim of translating his research findings to targeted intervention programs and clinical practices that are most appropriate for these populations. Lately, he has focused his attention on the disproportionate impact of COVID-19 on racial and ethnic minorities in places like the UK, the US, and the Netherlands.

He is a Professor of Global Migration, Ethnicity and Health, and Principal Investigator at Amsterdam University Medical Centres, University of Amsterdam (AMC-UvA). He is also currently the Vice President of the Migrant Health section & Secretary of the Governing Council of the European Public Health Association; Scientific Chair of the Global Society of Migration, Ethnicity, Race & Health; and a fellow of the prestigious European Research Council (ERC) under the Consolidation Award program. He is the PI of the RODAM study & Pros-RODAM study (www.rod-am.eu), and the Horizon Europe projects: Generation-H and MiPiD projects. He has published extensively and edited several books. He is a member of the WHO task force on NCDs in Migrants and was also a member and a rapporteur of the Planning Committee for WHO Global Consultation on Migrant Health. He is a member of the Lancet Racial Equality Advisory Board and the European Hypertension Society Workgroup on Hypertension & Cardiovascular Risk in Low Resource Settings. He is also a member of the European Academy. Prof. Agyemang serves as a member of several scientific advisory boards. He is Section Editor for Journal of the American Heart Association (JAHA), an Associate Editor for Internal and Emergency Medicine, and serves as Guest Editor and Editorial Board member for several journals.

4 July: 11:30 – 13:00

Artivism Presentations – Chairs: Alice Scavardana and Veronica Moretti – Room K.101

Ageing and Health, Regular Session – Chair: Francesco Miele – Room K.102

Supporting a partner with advanced dementia: The intersection of ageing, masculinity, and care

Edward Tolhurst (Staffordshire University)

Introduction

This presentation draws upon data from research that evaluated the experience of male spousal carers of women with dementia. The focus of this sample allows for evaluation of the gendered experience of male carers. The influence of gender upon the experience of men is an under-examined feature of social scientific health research: gender is a crucial factor shaping health and health-related behavior, but rarely is men's experience analyzed through the lens of gender (Evans et al, 2011). The tendency is strongly reflected within research on dementia and dementia care (Bartlett et al, 2018). While it is a challenge to ascribe distinctive gender-related factors to experience, the alternative approach (overlooking the influence of this key feature of social location) can only offer a distorted and inchoate grasp of the experiential domain. Caring is culturally constructed as a feminine

quality, aligned with maternal values (Ungerson, 2000); in contrast masculinity is typically associated with the economic sphere and the 'breadwinning role'. In terms of the domestic milieu, prevailing cultural standards require women to take care of men rather than vice versa (Boyle, 2014; Rykkje & Tranvåg, 2019). With these societal values as a context, caring is likely to be encountered as a gender-nonconforming phenomenon for men (Coston & Kimmel, 2013).

Methodology

To examine how older men navigate the experience of care, the following objectives were adopted: to evaluate how relationships are sustained and developed with other family members; to investigate how access to professional services and support groups are negotiated; to explore how broader social and cultural influences shape experience of the caring. A qualitative research approach was adopted, that included eight semi-structured interviews with male carers. Data was analyzed via thematic analysis (Braun & Clarke, 2022). A distinctive aspect of this study was that men had experience of supporting a partner with dementia with severe dementia. Within the sample, three men were living on their own as their partner had died; three men took part in the interview on their own as their partner lacked mental capacity (although they both still lived together in the family home); and for two men, their partner had moved to residential care.

Results

The qualitative data illuminate multiple dimensions of experience in relation to care, including intersecting factors of age and masculinity. Three principal themes provide a platform for the exploration of these matters: dealing with illness and behavioral change; negotiating relationships and support; and making sense of care responsibilities. These show how men seek to reconcile the gender nonconforming practice of care, with values more typically associated with masculinity such as practical endeavors and skills (see also Coston and Kimmel, 2013). Dealing with advanced dementia can shift the emphasis of care towards specific treatment and interventions, alongside a reduction to a breadth of relational engagement. For some men the successful engagement with interventions on behalf of male carer bolstered their sense of self-worth: placing greater emphasis on instrumental input than relational competence. It also shows how some of the potential challenges of caring for a person with advanced dementia, such as dealing with aggression, prompted concerns and the requirement for coping strategies. For some men these concerns were based on the anticipation that they could themselves have reacted aggressively in response to such challenges. In addition, men also discussed some of the benefits of accessing social support, but also discussed some of the constraints they encountered in engaging with such services.

Conclusion

This research demonstrates that the experience of dementia and care must account for complex, intersecting characteristics of those experiencing the condition first-hand. As a qualitative study no claims to generalizability are asserted. However, the findings offer transferable insights on the gendered basis of relationships and care. Policy and practice must be configured in a manner that is sensitive to the complex basis of personal experience and relational conditions. Since associations with care and caring practices are highly gendered, support and intervention programs can also be configured according to the same gendered logics. A more textured understanding of the gendered basis of dementia and care is required to tackle the needs of male (and female) carers more effectively.

Loneliness and cognitive decline in ageing Europe – A longitudinal study

Johanna Bristle (Catholic University of Applied Sciences Munich), Tessa-Virginia Hannemann (SHARE BERLIN Institute), Melanie Wagner (SHARE BERLIN Institute), Ella Cohn-Schwartz (Ben-Gurion University)

Introduction

Cognitive functioning is essential for leading a self-determined life at old age. However, loneliness is considered a risk factor for cognitive health and is on the rise in ageing societies. The current study examines the relationship

between loneliness and cognitive functioning, investigates short-term and long-term consequences, and explores regional differences across Europe. Previous studies focusing on the relationship between loneliness and cognitive decline have been run on samples from individual countries (e.g. Shankar et al. 2013, Yin et al. 2019, Zhong et al. 2017) although prior research showed that country differences and cultural context play an important role in the experience of loneliness (Sundström et al. 2009, Fawaz and Mira 2023). Therefore, there is reason to believe that cultural context also plays a role for the relationship between loneliness and cognitive decline. We thus pose the following research questions: (1) Does loneliness precede cognitive function? (2) Do these associations differ throughout Europe – and if so, how?

Methodology

We use panel data from the Survey of Health, Ageing and Retirement in Europe (SHARE; Börsch-Supan et al. 2013) from over 34,000 individuals aged 50+ in 14 European countries (Austria, Germany, Sweden, Spain, Italy, France, Denmark, Switzerland, Belgium, Czech Republic, Poland, Luxembourg, Slovenia and Estonia) and Israel with at least four participation rounds in the time period from 2011 to 2020. The longitudinal analysis applies cross-lagged panel models with fixed-effects (ML-SEM, following Leszczensky and Wolbring 2019). We measured cognitive function by a recall task which tests verbal episodic memory. An average of recalled words from both immediate and delayed recall tasks was used to score recall, thus ranging between 0-10, following Fawaz and Mira (2023). Our main variable of interest, loneliness, was measured using the UCLA Short Loneliness Scores, and introduced into the model as standardized additive scores that measure current and prior loneliness (two years lag). We control for other known risk factors, such as social isolation, age, depressive symptoms, or physical activity.

Results

Based on the longitudinal analysis, we found that older people experiencing loneliness have reduced recall scores. In addition, prior loneliness still affects current cognitive functioning (two years later). Our cross-national results show that the relationship between loneliness and cognitive decline differs across European regions, showing the strongest predictor in Northern Europe. Taking a more substantive macro-level indicator to group countries, we found that the country differences were pronounced when considering countries' average levels of loneliness. The countries with lower levels of loneliness showed a stronger link between loneliness and cognitive decline. This might be due to the higher stress caused by experiencing loneliness in these countries. In countries where loneliness is high, the association between loneliness and cognition is not statistically significant.

Conclusion

Loneliness is negatively associated with both current and future cognitive function. Country characteristics, such as the general loneliness level in a country, can modify this relation. The study goes beyond single-country studies by using a harmonized European cross-national dataset and exploring country group variations in several dimensions. Due to data capacity and the requirements of the cross-lagged panel models, we could not estimate the loneliness-cognition link for each country. While introducing a temporal order by applying a novel panel model to reduce potential bias of reverse causality, we are limited in concluding on the causal nature of the relationship. However, there is some evidence suggesting the relationship between loneliness and cognitive decline is cyclical in nature (Yin et al. 2019). Irrespective of the specific causal pathways between loneliness and cognition, we picture loneliness in later life as a risk factor for cognitive health that is modifiable, providing an impetus for political and societal efforts to reduce loneliness.

Social network dynamics and cognitive functioning in European older adults: Insights from SHARE

Maud Wieczorek (Swiss Centre of Expertise in Life Course Research LIVES), Clément Meier (University of Lausanne), Sascha Zuber (University of Geneva), Andreas Ihle (University of Geneva), Matthias Kliegel (University of Geneva), Jürgen Maurer (University of Lausanne)

Introduction

As the aging population grows, cognitive decline has emerged as a critical concern. Prior longitudinal studies have suggested that socially enriched environment may help maintain cognitive functioning in old age. However, these studies typically used a single indicator of the interpersonal social environment or focused on the functional and quantitative characteristics of the social network, overlooking the impact of qualitative aspects of the relationships maintained. Moreover, they are constrained by sample size or follow-up duration. The present study aims to investigate the association between changes in social network over nine years, both in terms of quality and quantity, and subsequent cognitive functioning among a large population-based sample of European adults aged 50 and older.

Methodology

We used data from 9,760 respondents to wave 4 (2011), wave 6 (2015), wave 8 (2019/2020) and wave 9 (2021/2022) of the Survey of Health, Ageing, and Retirement in Europe (SHARE). Cognitive functioning, assessed in wave 9, was measured using three key cognitive abilities: immediate memory, delayed memory, and verbal fluency. Immediate and delayed memory abilities were evaluated using a 10-word list recall test and verbal fluency was measured by the number of distinct animals a participant could name within one minute. These abilities were scored, standardized into z-scores based on age and education categories, and averaged to create a global cognitive score. Social network characteristics, including size, geographical proximity, contact frequency, closeness of members, and satisfaction, were measured in waves 4, 6, and 8.

Respective associations between changes in each social network characteristic and cognitive functioning were initially explored using separate ordinary least squares regression models, controlling for socio-demographic and health characteristics measured in wave 4: sex, age, education levels, partnership status, subjective financial situation, living area, country of residence, self-rated health, prevalent depressive symptoms, presence of limitations in activities of daily living and global cognitive score. The models additionally controlled for the presence of depressive symptoms and limitations in activities of daily living measured in wave 9. A final ordinary least squares regression model was run including all network characteristics, controlling for the same above-mentioned set of covariates.

Results

About 21.2% of respondents reported a decrease in social network size, 13.4% in geographical proximity, 11.8% in contact frequency, 4.8% in the closeness of members, and 3.6% in satisfaction between wave 4 and wave 8. Preliminary analysis indicated that decreases in social network size (Average Partial Effect [APE]=-0.04, $p<0.05$) and satisfaction (APE=-0.08, $p<0.05$) were individually and significantly associated with lower cognitive functioning in wave 9. We did not find any significant association between the other social network characteristics and cognitive functioning. When considering all social network characteristics in a comprehensive multivariate model, only decreased satisfaction with social network remained significantly associated with lower cognitive functioning in wave 9 (APE=-0.08, $p<0.05$).

Conclusion

Our preliminary multivariate analysis suggests a significant and consistent association between decrease in social network satisfaction and subsequent lower cognitive functioning among European older adults. These findings suggest the importance of qualitative rather than quantitative aspects of social network for cognitive health, offering potential avenues for interventions. Moving forward, we intend to use more advanced statistical models, such as cross-lagged panel models, to further explore these dynamic relationships and support the development of targeted strategies for cognitive health maintenance in older adults.

The incidence of disability retirement among persons aged 50 and over by birth cohort in Finland

Mikko Laaksonen (The Finnish Centre for Pensions)

Introduction

People's work ability declines with age. This is reflected in the fact that the risk of disability retirement increases sharply after the age of 50. Disability pensions incur large costs and are an important reason for shortening working lives. It is therefore important to follow and try to anticipate the changes in disability retirement.

The incidence of full disability retirement in Finland has decreased over the last 20 years. In recent years, however, there have been strong fluctuations in both directions, which may have been influenced, for example, by the COVID-19 pandemic. It is not clear in which direction the incidence will develop in the future. However, the incidence of partial disability retirement has constantly increased, especially in the older age groups. Examining the changes in disability retirement by birth cohort can provide more timely information on future changes than tracking trends over time.

Methodology

The study is based on a register data covering the entire Finnish population. All persons born between 1945 and 1971 who were not receiving a disability pension at the age of 50 were included. The study examines the incidence of disability retirement in these cohorts by 1-year age groups between the ages of 50 and 63, which was the lower age limit for old-age pensions for those born before 1955. Since then, the retirement age has been gradually increased. The incidence of disability retirement was calculated by dividing the number of disability retirees at a given age by size of the birth cohort at that age. As data were available until 2022, those born between 1945 and 1959 can be studied from age 50 to retirement age (dashed lines in the figures). Those younger than this can be studied over shorter periods (solid lines).

Results

The incidence of full disability retirement was highest in the cohorts born between 1945 and 1950. Since 1951, the incidence of full disability retirement has decreased sharply, especially for those under 60. The decrease continues also in younger birth cohorts that cannot yet be examined up to the age of 63.

The incidence of partial disability retirement has increased strongly, especially for those aged 57 and over. While the incidence of disability retirement at the ages around the age of 60 was 0.2% for those born in 1945 and 1946, it was 1.2% for those born between 1957 and 1959. It can be assumed that the decrease in full disability retirement is partly compensated by the increase in partial disability retirement. However, for the cohorts born in the 1960s, the incidence of partial disability retirement decreases. While it is not yet possible to examine the incidence of disability retirement in the oldest age groups of these cohorts, the incidence in the younger age groups is clearly lower than for those born in the 1940s and 1950s.

Conclusion

The incidence of disability retirement increased until the cohorts born in the late 1940s. Among those born later, the incidence of both full and partial disability retirement is gradually lower than for earlier cohorts of the same age. Although the age of partial disability retirement has increased slightly, this suggests that the incidence of both full and partial disability retirement will decrease in future years.

Sexual and Reproductive Health, Regular Session – Chair: Nina Van Eekert – Room K.103

“Ideal” versus “difficult” clients in Swiss maternity care: Inequalities and normative views

Irina Radu (Zurich University of Applied Sciences), Alessandra Polidori (University of Neuchatel), Michael Gemperle (Zurich University of Applied Sciences), Didier Ruedin (University of Neuchatel), Gianni D'Amato (University of Neuchatel)

Background

Maternal care is a key area of health care and women's and other pregnant persons' experience of pregnancy, birth and postpartum is central for their health and wellbeing as well as for the health and wellbeing of their babies throughout the lifespan. As in other countries, this is the case in Switzerland where high-quality maternal care is provided. Yet, certain groups are consistently shown to have higher than average mortality and morbidity rates. This especially applies to women and pregnant people born outside of Switzerland, those whose parents are born outside of Switzerland, people who are socioeconomically disadvantaged, as well as people with multiple vulnerabilities. International literature points to different systemic, institutional, and individual barriers that reinforce these disparities in maternal health, like the absence or inadequacy of health information in different languages, the lack of interpreters, the cost of consultations. Moreover the attitudes of health care providers also play a role, with studies showing that patients are routinely evaluated according to their perceived "social worth". Additionally, in maternal care, the role of gender stereotypes and normative views of "good motherhood" also play an important part in shaping health care providers' attitudes.

Objectives

The aim of our study is to provide insights into how systemic, institutional factors as well as professional attitudes contribute to the creation and maintenance of inequalities in maternal care.

Methods

We have designed a mixed-methods approach in three stages. In the first stage of the project we are conducting qualitative in-depth interviews with experts in maternal care, migration and health, as well as health care providers working in maternal care, from the German, French and Italian speaking parts of Switzerland. With these preliminary results we will move to the second stage which consists of a quantitative survey of health care providers. Finally, the third stage of the project will consist of focus groups with experts and health care providers in which results from the previous phases will be reflected back and contextualized. At this stage, we have preliminary results from the first stage of the study.

Preliminary results from the qualitative interviews with experts in maternal care, migration and health reveal that maternal care in Switzerland is often systemically and institutionally structured around an idealized client profile. This profile aligns with prevailing social norms and expectations: The individual typically speaks a national language fluently, is in a stable partnership, well-integrated into the local community and isn't in an economically precarious situation. In terms of norms of "good motherhood" the woman or pregnant person is expected to be well informed about the way maternal care in Switzerland works, to prioritize the wellbeing of the foetus, actively minimize risks through lifestyle adjustments, and engage with medicalized approaches to pregnancy, birth and postpartum care.

Clients who do not conform to this idealized type are often perceived as "difficult" by health care providers. This perception arises partly due to the divergence of these clients' social contexts from the normative expectations embedded within institutional processes and professional practices in maternity care. These discrepancies highlight the significant role that social norms play in shaping health care experiences and outcomes. Furthermore, our findings indicate that the stark division between "social" and "health" roles within hospitals - both on an institutional level and in the health care providers' self-definition - further exacerbates the challenges in meeting the needs of those who deviate from the norms, such as women and pregnant people who are migrants, or perceived as part of a cultural minority, do not speak a national language, are in an economically precarious situation, or those with multiple vulnerabilities. This division underscores the impact of normative frameworks in shaping health provision and accessibility.

The concept of sexual wellbeing: Measuring what matters for young people and adolescents in sexual and reproductive health

Lore Remmerie (Catholic University Leuven), Kristien Michiels (Catholic University Leuven), Heidi Mertes (Ghent University)

Introduction

The definition of sexual health has evolved over the past decades, with the most recent WHO working definition of sexual health dating from 2006. The evolution illustrates a shift away from the traditional focus on the absence of diseases, to a more comprehensive understanding, by acknowledging the importance of a positive approach, aspects of well-being, pleasure, and sexual rights for all (WHO, 2017).

Expanding on this paradigm shift, numerous academics advocate actively integrating a "positive approach" into research, programming, and service delivery practices within the field of SRH, acknowledging the importance of pleasure and moving beyond the traditional convention of what is seen as "normal" or "healthy" (Harden, 2014; Michiels et al., 2016; Kågesten & van Reeuwijk, 2021; Philpott et al., 2021). This is especially relevant for adolescents and young people, where moral debates regarding whether their sexual behavior is problematic and morally wrong, as opposed to recognizing it as an integral aspect of their healthy development, have historically shaped interventions and research paradigms (Halpern, 2010; Harden, 2014; Kågesten & van Reeuwijk, 2021).

The concept of sexual wellbeing emerged as a promising outcome to embrace a sex-positive approach and expand the scope of SRH research. The concept was discussed in 2010 by a WHO working group, with the aim to offer a broader interpretation of sexual health. Considering its cultural and context-specific nature, the WHO did not provide an official definition or specify indicators for this concept (WHO, 2010). This lack of clarification does not align with the needs in the academic field where the interest in the concept of sexual wellbeing is clearly growing. A rapid review on the concept of sexual wellbeing identified major gaps in its conceptualization, demonstrating the limitations of not having an appropriate framework (Lorimer, 2019).

A guiding framework to define and measure sexual wellbeing in research is crucial. The framework must however avoid oversimplification, allowing space for a broad range of interpretations. While existing efforts to conceptualize sexual wellbeing provide valuable initial insights, they lack inclusivity towards various youth perspectives and diverse cultural contexts (Mitchell et al., 2021; Kågesten & van Reeuwijk, 2021). Consequently, it is crucial to undertake additional measures to address these limitations.

To address these gaps, this study aims to contribute to the development of a comprehensive and inclusive framework for sexual well-being, and integrate the viewpoints of young individuals through collaborative co-creation in shaping this framework.

Methods

As a first step, a modified Delphi study design was done, involving three iterative online rounds engaging panel members (N=15) representing young individuals with diverse backgrounds in terms of gender, sexual orientation, and ethnicity. During the first round, panel members were asked to participate in an online asynchronous brainstorm exercise on Padlet, an online platform, exploring their understanding of the concept of sexual well-being. During the second round, three online focus group discussions were organized to discuss results of the first round, and reflect on the scientific literature. After analysis of the second round, a draft conceptual framework of sexual wellbeing and a definition were shared, together with a feedback template to allow panel members to give feedback. In the next stage, we will extend this research, and recruit young researchers (N=15) in different contexts, to conduct their own research projects to conceptualize sexual wellbeing collaboratively. As a final step a Flemish scale will be developed for measuring sexual wellbeing in youth and adolescents. This will involve a two-round Delphi methodology for content validity, and a web-based survey to assess scale validity.

Results

The first step provided preliminary results on the concept of sexual well-being based on the perspective of an online panel of 15 young people representing countries from Europe, Asia, Africa, and South-America. The framework acknowledges the subjective nature of sexual well-being. It underscores the necessity of creating enabling environments that facilitate informed decision-making, bodily autonomy, consent, exploration, and self-awareness regarding sexual health, experience of pleasure, communication, ability to be comfortable, and self-esteem. Finally, sexual well-being encompasses access to sexual and reproductive health information and services, acceptance, respect, comfort, safety, and freedom from coercion and violence within society. The upcoming stages will enhance this concept by incorporating perspectives from larger groups of young people and lay youth. These stages aim to establish context-specific conceptualizations and a cross-cultural understanding of sexual wellbeing, featuring clear indicators. Finally, based on the cross-cultural conceptual model, we will develop a scale for measuring sexual wellbeing in Flanders.

Conclusion

This study introduces an initial framework for redefining sexual well-being, yet it lacks insights from lay young people and does not offer a practical translation into measurement tools. We aim to overcome these limitations in the upcoming phase of the research project.

Uncovering racism in maternal care: Building inclusive care through methods of co-production and mutual learning

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Introduction

Racial inequalities in healthcare are documented across settings in the Global North. In maternal care, racialized minoritized women experience worse health outcomes, such as increased risk for stillbirth, preterm birth, and higher maternal and perinatal mortality. Factors contributing to inequalities are complex, ranging from maternal factors, such as women's health status, educational level, and health literacy, to socioeconomic factors. However, these factors do not solely account for racial inequalities such that these inequalities persist even when these factors are controlled for, with research showing that these inequalities are also connected to suboptimal care. Although research on racism in healthcare points to healthcare providers' racial bias and its association with adverse diagnosis and treatment choices, research on racial inequalities in maternal care has focused on *documenting* inequalities rather than examining *how* racism contributes to these inequalities. In light of this, we will conduct a project to uncover racialization in maternal care, and contribute to antiracist and inclusive maternal care through methods of co-production and mutual learning.

Methodology

The study will be carried out in Sweden and the United Kingdom during 2024-2026. Departing from an intersectional understanding of racism, we will use an ethnographic methodology to observe interactions between racialized minoritized women and healthcare providers to uncover racialization processes. Ethnographic observations will be combined with qualitative interviews with women and providers to examine differential experiences and views on racism. Through co-production and mutual learning methods, we will (in the second half of the project) convene discussion groups with racialized minoritized women and providers to solicit discussions on racism and design antiracist tools and interventions. From beginning to end, we will work with an advisory group consisting of racialized minoritized women, providers and policymakers. The group will assist the research group in discussing racism and the project setup, recruiting participants, and co-producing tailored antiracist tools and guidelines for improving organizational routines in maternal care.

Results

The current project builds on previous research on racism in healthcare, including maternal care in both Sweden

and the UK, and other contexts in the Global North. Research in Sweden and the UK shows that providers in maternal care view racialized minoritized women as too demanding, too emotional and too dramatic. Further, research also shows racialized minoritized women's symptoms are not taken seriously and their pain often minimized. Recent research on racialized talk in healthcare has shown that racialized talk against racialized minoritized healthcare users is used to categorize minority users as 'bad' users and their health complaints as 'unworthy' by labelling their symptoms as 'ethnic', and 'cultural'. The devaluing of racialized minoritized users through talk further justifies inadequate care. While racialized talk and the devaluing of racialized minoritized women is common, recent research has also shown that healthcare providers tend to obfuscate racism in healthcare by emphasizing healthcare neutrality and equality regulations, blaming minorities for racism and viewing racism as an individual aberration. Research in the UK has also shown that racialized minoritized women in maternal care are perceived as too demanding, too emotional and too dramatic. Further, research also shows racialized minoritized women's symptoms are not taken seriously that staff perceive healthcare users from racialized minorities in maternal care as demanding, too emotional and dramatic

Departing from these findings, we expect the study to deepen our knowledge and understanding of 1) How racialized minoritized women are treated in comparison to racialized majority women regarding their symptoms and the delivery of care; 2) Racialized institutional routinised medical praxis; 3) Possible differences in racialization between various groups of racialized minoritized women; and 4) Possible contextual differences in racialization in Sweden and the UK given the differences in colonial and neo-colonial aspects and modes of racialization. Based on the study findings and methods of co-production and mutual learning, we also expect the study to produce tailored antiracist tools and guidelines to improve organizational routines concerning maternal care.

Conclusion

The Lancet and Nature's series on racism in healthcare push the need to view racism as a structural social determinant of health and calls for using an intersectional analysis. We will do this by highlighting the voices of racialized minoritized women, often rendered invisible regarding their experiences in maternal care. Since interventions in maternal care lack a clear conceptual intersectional framework of racism, the theoretical knowledge produced through this study represents a needed approach to improving the quality of care. Further, by developing antiracist tools through co-production and mutual learning with women and providers, the project will contribute to possible policy changes in maternal care in Sweden and the UK.

Sexual wellbeing among young people in remote rural island communities in Scotland

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Introduction

It has been identified that rural young people face barriers to accessing support for their sexual wellbeing such as availability and transport, knowing healthcare staff personally, and fear of being judged negatively within their community. These factors may contribute to widen health inequalities and expose young people living in rural areas to increased risk of poor sexual wellbeing. Adolescents living in rural communities which hold religious, traditional, and conservative values may avoid accessing contraception services out of fear of being judged negatively.^{1,2} Such issues have been highlighted previously for young people in rural areas of Scotland.³ Social isolation and lack of access to information or youth services can exacerbate health risk.⁴ LGBT+ adolescents living in rural areas of Scotland are more likely to report feeling lonely and of experiencing prejudice or discrimination within their local community than their urban counterparts.⁵ Little is known about the current needs of adolescents residing in remote rural island communities (RRICs).

Methodology

A cross sectional mixed methods sequential explanatory approach was used to address the study aim. 473

adolescents aged 13-18 took part in an interactive survey in secondary schools, 16 young people took part in focus groups. The geographical location of the research was the Outer Hebrides (current population 26,500), a chain of islands off the West Coast of Scotland. The islands lie approx. 40 miles (65 km) from the Scottish mainland. Analysis included descriptive, inferential statistics, and thematic analysis.

Results

59% ($n=279$) of participants held the perception there was no support, or did not know if there was support, about condoms and contraception in their local area. 48% ($n=227$) said that free condoms were not easily available for local young people. 60% ($n=283$) said they would not use youth services if they were locally available. 59 % ($n=279$) said they did not receive enough Relationships Sexual Health and Parenthood (RSHP) education. Opinion differed significantly by gender, school year group, and sexual orientation. Qualitative analysis identified 3 key themes (i) Alone yet visible, (ii) Silence and Disapproval, (iii) Safe Spaces, with an underpinning theme of Island Cultures.

Alone yet visible. Participants expressed the influence both of spatial and social isolation when considering accessing support. Being situated geographically on, and within, a small island community constituted and contained social relations that made them easily identifiable. Young people identified that confidentiality and anonymity were important needs when considering accessing sexual information, condoms, and advice, however perceived that the island context and culture was at odds with these needs,

Silence and Disapproval. Accessing a local sexual support service for young people or buying condoms at the local shop was expressed as impossible. Participants perceived an automatic disapproval from others towards subjects involving relationships or sex, this was identified as a strong local social norm embedded in the cultural religious heritage of the islands. Experiences of RSHP education at school reinforced the perception of silences around this subject.

Safe Spaces. Safe spaces were seen as separate from the rural locale, networks perceived as not 'belonging' to adults and older community members, such as social media and online information were identified as safe places for sexual expression and learning. The 'mainland' was idealized as an anonymous space when discussing the idea of accessing support for sexual wellbeing. Participants expressed perceptions of being a different person unrelated to the islands, and thus 'free' to be themselves,

Conclusion

A need for further sexual wellbeing support that addresses the complexities and challenges for young people residing in RRICs is identified. The intersectionality of being LGBTQIA+ and residing in this context may increase the experience of inequality in sexual wellbeing support. The findings identify the need for an intersectional approach to the creation of place-based sexual wellbeing support for young islanders. This support should be co-produced with adolescents living in the local and social context.

Social Inequalities in Healthcare Use, Thematic Session – Chair: Heta Moustgaard – Room K.201

Pregnancy experiences of transgender and gender expansive individuals: A scoping review from a critical midwifery perspective

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Background

Evidence suggests that transgender and gender expansive people are more likely to have suboptimal pregnancy

outcomes than cisgender people. The aim of this study was to gain a deeper understanding the role of midwifery in these inequities, by analyzing the pregnancy experiences of transgender and gender expansive people from a critical midwifery perspective.

Methods

We conducted a systematic scoping review. We included 15 papers published since 2010, reporting on pregnancy experiences of people who had experienced gestational pregnancy at least once, and were transgender, non-binary or used other gender expansive identities.

Results

Three themes emerged from our data analysis: 'Navigating identity during pregnancy', 'Experiences with mental health and wellbeing', and 'Encounters in the healthcare system'. Although participants reported positive experiences, their ability to experience their pregnancy in a gender-affirmative way was shaped by experiences that impacted access and quality of care, such as trans negativity and transphobia in social and prenatal care settings.

Discussion

In order to improve care outcomes of transgender and gender expansive people it is necessary to counter anti-trans ideologies by 'fixing the knowledge' of midwifery curricula. This requires challenging dominant cultural norms and images around pregnancy, reconsidering the way in which the relationship between 'sex', 'gender' and 'pregnancy' is understood and given meaning to in midwifery, and applying an intersectional lens to investigate the relationship between gender inequality and reproductive inequality of people with multiple, intersecting marginalized identities who may experience the accumulated impacts of racism, ageism, and classism. Future research should identify pedagogical frameworks that are suitable for guiding implementation efforts.

Profile of the CHW within breast cancer screening: focus group interviews with the target population

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Background

In 2021, 11.319 women in Belgium were diagnosed with breast cancer. Despite the Breast Cancer Screening Program a significant inequality in participation in breast cancer screening persists in Belgium. Limited health literacy appears to be one of the major causes of this inequality. To address this issue and disseminate information effectively to the target group, the utilization of a community health worker (CHW) becomes a viable strategy. CHWs have been actively engaged for numerous years in low and middle-income countries, providing an integrated approach to breast cancer screening. To our knowledge, little is known about the role and profile of the CHW in Belgium and its potential impact on breast cancer screening.

Objective

This research aims to examine the profile of the CHW within breast cancer screening in Flanders.

Methods

Profile characteristics of the CHW within breast cancer screening were investigated through focus group interviews. The collected data were analyzed using a Qualitative Content Analysis in NVIVO.

Results

In total, 28 women participated in the focus group interviews (n=4). These women expressed a preference for a female CHW with prior experience in undergoing mammography and dealing with breast cancer. Additionally, it is crucial that the CHW possesses sufficient knowledge about breast cancer screening. The CHW should also

possess qualities such as empathy, trustworthiness, and social, emotion-regulating, listening, digital, communicative, and language skills.

Discussion/Conclusion

Various characteristics, essential for a CHW involved in breast cancer screening, were identified during the interviews. These characteristics should be taken into account during the selection process to ensure the selection of an appropriately qualified CHW capable of addressing the existing inequalities in breast cancer screening.

Too little, too late? Mental healthcare utilization preceding deaths of despair among men and women

Kristian Heggebo (NOVA – Norwegian Social Research), Jørn Ljunggren (NOVA – Norwegian Social Research)

Background

Women report poorer health status, utilize healthcare services more often, and receive health-related benefits to a larger extent, compared to men. Women nonetheless live considerably longer than men do, with a gender difference in life expectancy of around 3-4 years in Norway, the present research context. That women appear to be sicker whereas men die quicker is sometimes referred to as the “gender health paradox”. Marked gender differences have also been observed on the mental health domain, including the so-called “deaths of despair”, i.e., suicides, drug overdoses, and alcohol-related liver diseases, with noticeably higher mortality from these causes among men than women.

Objectives

Gender differences in utilization of mental healthcare services is one potential reason why men have considerably higher mortality from diseases of despair. Men might be less inclined than women to contact health services while experiencing mental distress. Mental health conditions experienced by males may therefore either develop into more severe and complex health problems before treatment is sought, or alternatively be left untreated altogether. In contrast, females could, on average, be more inclined to seek out professional help for their mental health issues and thereby prevent the problems from deepening further. Accordingly, the current study examines mental healthcare utilization among men and women who die from diseases of despair.

Methods

We analyze population-wide administrative register data, covering all registered inhabitants in Norway, with descriptive statistics and various regression techniques (logistic regression analyses, linear [ordinary least squares] probability models, and Cox proportional hazards models). Men and women aged 15-69 (cf. the WHO definition of premature mortality) who die from diseases of despair during 2015-2017 are followed in their access to and use of in- and outpatient hospital care for mental health conditions (ICD-10-codes F00-F99) during six preceding years (2009-2014). The statistical models are adjusted for sociodemographic characteristic (age, education, marriage, immigrant background, employment, income sources) measured in baseline (2008).

Results

Deaths of despair were more common among men (N=1337) than women (N=522) in Norway during 2015-2017. Females who died from diseases of despair utilized significantly more mental healthcare services, compared to their male counterparts. Roughly half of men and approximately one-third of women did not have any contact with specialized services for mental and behavioral disorders prior to deaths of despair. Recipients of social assistance (OR=6.34 men; OR=6.58 women) and disability benefits (OR=2.33 men; OR=2.92 women) had a particularly high likelihood of dying from diseases of despair.

Conclusion

The current study has shown, first, that a sizeable share of those who died from diseases of despair had no

contact whatsoever with specialized mental healthcare services during a six-year-period prior to death. Second, males were treated less often for mental and behavioral disorders in the years before they died from diseases of despair, compared to females. Third, recipients of social assistance and disability benefits had a particularly high deaths of despair likelihood, among men and women alike. It seems as if mental health conditions lead to permanent economic marginalization (i.e., receipt of social assistance and disability benefits), which in turn deepens the mental health problems experienced, and may ultimately end in deaths of despair. This negative chain of events appears to be stronger for men than women in the comprehensive Nordic welfare state context. In conclusion, gender inequalities will tend to emerge on the mental health domain, despite the presence of a universal healthcare system with few out-of-pocket payments.

Using decision trees to identify intersectional risk groups for never attending breast cancer screening, Germany

Núria Pedrós Barnils (University of Bremen; Leibniz ScienceCampus), Benjamin Schüz (University of Bremen; Leibniz ScienceCampus)

Introduction

Malignant neoplasm of the breast was the fifth leading cause of death in Germany in females with 18,500 deaths in 2020 (1). Since 2009, Germany has fully implemented an Organized Screening Program, where women aged 50 to 69 years are bi-annually invited for breast cancer screening (BCS) (2). The participation rates have fluctuated, and in 2021, approximately 12% of the targeted women self-reported having never attended BCS in their lifetime (3). Discovering intersectional groups of women who never attend is key to developing tailored public health interventions. Traditionally, in statistics, predictors (e.g., sociodemographic variables) or intersectional predictors (e.g., cross-categorical groups) are chosen by the researchers a priori based on knowledge of the literature. Using explorative quantitative methods, such as decision trees, allows for an inductive approach to identifying intersectional groups to be used as predictors in a regression analysis. In this study, we compare two intersectional approaches to determining intersectional groups at higher risk of never attending breast cancer screening in Germany: cross-categorical regression analysis based on predictors derived from the available literature and cross-categorical regression analysis using intersectional groups based on data-driven decision trees as predictors.

Methodology

Women aged 50-69 years old were drawn from the German sample of the 2020 European Health Interview Survey, which targets the adult population > 15 years old living in private households. The survey sample size was 23,001 respondents, corresponding to 21.6% of the invited participants (N= 23,001; 21.6% response rate) (4). Using available indicators of socioeconomic status based on the PROGRESS-Plus framework, we first fitted multivariate logistic regression models to estimate the odds ratio (OR) with BCS non-attendance as the outcome and literature-informed intersectional social positions as the predictors with the descriptively best-off group as the reference category. Secondly, we employed explorative decision trees (Classification and Regression Trees (CART), C50, and Conditional Inference Trees (CIT)) with the total sample size using all available indicators of socioeconomic status to find homogeneous subgroups of women based on self-reported never attending BCS. Then, we carried out a logistic regression with the subgroups identified from the best-performing decision tree as predictors to estimate the OR of never attending BCS.

Results

In the first approach, we operated socioeconomic status (SES) and migration background as predictors (i.e., high SES born in Germany, low SES born in Germany, high SES not born in Germany, low SES not born in Germany). Adjusting for age, we found that high SES women not born in Germany had 47% higher odds of attending BCS than high SES women born in Germany ($p=0.059$). In the second approach, and after hypertuning the decision trees, the best-performing tree was CART ($cp= 0.005563425$ and $maxdepth=5$) with a balanced accuracy of 60.73% and a sensitivity performance (detection of true positive cases) of 67.52%. Then, we conducted a logistic

regression model adjusting for age with the best-off intersectional subgroup (group 8) as the reference category. Intersectional subgroups 1, 2, and 4 showed statistically significant higher odds of 2.93 ($p=0.012$), 2.84 ($p=0.009$), and 2.52 ($p=0.020$) of not attending BCS compared to the reference group. All results are preliminary.

Conclusion

Decision trees help identify intersectional groups that would otherwise be undetected. This approach's enhanced precision and detailed insights can substantially contribute to developing health prevention programs that strive for equitable access to healthcare services.

Who got tested for covid-19? – Linking 0.5 million PCR-tests to administrative registers in Sweden, 2020

Olof Östergren (Stockholm University), Emilie Counil (French Institute for Demographic Studies), Arizo Karimi (Uppsala University), Tove Fall (Uppsala University), Jonas Björk (Lund University), Karl Gauffin (Stockholm University)

Introduction

During the first year of the coronavirus pandemic, PCR testing was a crucial tool for epidemiological surveillance and for targeted interventions such as isolation of cases and contact tracing. While parts of the testing capacity were typically targeted at frontline workers or medically vulnerable groups, a substantive part of tests were initiated by individual members of the general public. The representativeness of incidence rates of covid-19, used by governments to track and manage the pandemic, then relies on that individual testing propensity is proportional across population groups.

Qualitative studies have revealed several motivations both to get tested and to avoid testing for covid-19 infection. For example, individuals may decide to get tested to protect themselves and the health of others, to improve their chances for better medical care and out of a sense of civic duty. Individuals may avoid getting tested for fear of negative economic repercussions and difficulties in navigating the medical system. Evidence from the UK, Switzerland and Sweden have indicated that affluent groups were more likely to get tested for covid-19, while simultaneously being more likely to develop severe complications from the infection. However, the determinants of testing behavior have not been extensively studied quantitatively, since individual-level data on tests, as opposed to detected infections, are scarce. The aim of this study is to investigate the demographic, socioeconomic and medical determinants on testing behavior using linked register data from Sweden.

Methodology

We rely on individual level data from the 1177-system, that was used by the public to order covid-19 tests in parts of Sweden. We focus on two large counties that used the system, Stockholm and Skåne. We link the data on tests to several administrative registers on demographic conditions, socioeconomic characteristics and use of medical services including prescription drugs and in- and outpatient care. We limit the population to individuals of working age, 30–64 years old, who were not employed in healthcare or social services because they were tested at work through separate channels. We also limit the observation period from 2020-07-01 to 2020-12-31 when testing was widely available and vaccines were not yet widely disseminated. Our final population comprised 1.56 million individuals and 0.47 million tests.

We estimate the probability of ordering at least one test during the observation period using a linear model with fixed effects for county and age. We assess testing propensity by gender, marital status, migration background, residence in an urban or rural area, educational attainment, income quartile, occupation (149 categories), medical risk factors, household members with medical risk factors and household members over the age of 70. We fit an identical model substituting testing propensity for hospitalization risk to benchmark how well the testing behavior reflects infection rates in different population groups.

Results

The testing rate was 33.2% in Stockholm and 32.7% in Skåne. The testing propensity was lower among men, the unmarried, migrants, those residing in a rural area, individuals with lower education and income, those that did have a medical risk factor and those with no household members with medical risk factors. Testing propensity also varied greatly by occupation with especially low testing propensity among the unemployed and in workers with routine manual tasks and high propensity in white collar workers. The associations with hospitalization risks were similar for some of the factors, for example marital status and having a medical risk factor in that married individuals and those with medical risk factors were more likely to get tested and hospitalized. On the other hand, having a high education, being born in Sweden with two Swedish-born parents and female gender were associated with higher testing rates but lower hospitalization risks. A higher income and having household members with medical risk factors was associated with a higher testing propensity but was not associated with hospitalization risk.

Supplementary analyzes revealed that the testing propensity varied greatly by the specific medical risk factor. Chronic respiratory diseases, obesity, rheumatoid arthritis and pregnancy were all associated with higher testing propensity. Diabetes, dementia, having undergone organ transplantation and chronic liver or kidney disease were all associated with lower testing propensity relative to those without risk factors, despite these conditions being associated with higher risks of hospitalization. Notably, the association between medical risk factors and testing propensity was of similar magnitude regardless of if it was the individual or a household member that experienced the condition.

Conclusions

A wide range of demographic, socioeconomic and medical factors are associated with testing behavior. The results suggest that protecting one's own health, but also that of others, was a strong motive. It is concerning that individuals in low socioeconomic positions and migrants had low testing rates given their high risks of severe covid-19. In order to successfully manage future pandemics, policy makers need to consider sociodemographic differences in testing behavior in the population.

Socioeconomic Status and Health, Regular Session – Chair: Malgorzata Mikucka – Room K.202

Debt and health trajectories in Switzerland, a multichannel perspective

Boris Wernli (The Swiss Centre of Expertise in the Social Sciences; University of Lausanne), Jacques-Antoine Gauthier (University of Lausanne), Tristan Coste (University of Applied Sciences and Arts of Lausanne), Stéphane Cullati (University of Fribourg), Caroline Henchoz (University of Applied Sciences and Arts of Lausanne)

Abstract

In Switzerland, as elsewhere, the relationship between debt and health remains under explored, even though household debt is a growing concern in many European countries. Previous research shows that debt can be a good predictor of poor health, independently of other measures of socio-economic conditions such as income, education and occupation.

However, an important limitation of most research is that it tends to study the relationship between debt and health problems cross-sectionally or over a short period of time. This ignores two facts, highlighted by qualitative data and debt counseling services. First, debt problems are often not transitory, but long-term trajectories consisting of phases of debt accumulation and repayment. Second, the negative effect on health is cumulative, due to the long-term stress associated with debt repayment.

To overcome these limitations, in a first paper we used sequence analysis to build up a typology of debt trajectories in Switzerland over the medium to long term (up to 18 years of follow-up). We showed that these

types are closely linked to the stages of the family life cycle, to the economic conditions of the household, and to cultural aspects (e.g. a greater propensity to over-indebtedness in the Latin regions of Switzerland) (Coste et al submitted). A clear association between baseline health and debt trajectories has also been demonstrated, with a better health and subjective well-being among those without debt, opposed to worse health and subjective well-being of those with a long history of debt.

In this second series of analyzes, we aim at taking simultaneously into account debt trajectories and trajectories of health based on indicators of somatisation as we consider that they are intrinsically linked to one another. Secondly, we look at the socio-demographic, socio-economic and life satisfaction indicators, all measured at baseline, associated with these joint trajectories.

We use data from the Swiss Household Panel, an annual longitudinal survey of a representative sample of the Swiss population. Our analyzes cover individuals aged between 20 and 45 in 2004 (wave 6) and followed up until 2022 (wave 24). Debt is measured by the self-reported frequency of arrears at the household level over the past 12 months (no, sometimes, often), which is the most widespread and most problematic type of debt in Switzerland. Somatic health is measured using four self-reported indicators relating to back and sleep problems, weakness and headaches, with 3 modalities (not at all, somewhat, very much).

First, we carry out multichannel sequence analyzes to identify multidimensional debt and somatic health trajectories. We then use regression techniques to examine the association of these conjoint debt and health trajectories with socio-demographic, socio-economic and subjective well-being characteristics.

Our preliminary results highlight the importance of taking into account the frequency, duration and timing of debt across trajectories in order to fully examine the relationship with health problems.

An intersectional approach to identifying risk groups for depressive symptoms in Germany

Daniel Lüdecke (Institute of Medical Sociology), Olaf von dem Knesebeck (Institute of Medical Sociology), Nico Vonneilich (Institute of Medical Sociology)

Background

There is an increasing interest in intersectional theory and corresponding analysis strategies in social epidemiological. Previous analyzes of inequalities in depression have so far analyzed the singular effects of inequality dimensions, without considering their interactions and interrelationships. However, the need to take interactions between these dimensions into account has been recognized, calling for new approaches to analyze intersectional strata. One proposal for an intersectionality analysis is the MAIHDA framework (multilevel analysis of individual heterogeneity and discriminatory accuracy). In this presentation, we used this approach to answer the following two research question: Which intersections were particularly significant in relation to depressive symptoms? Which socio-demographic characteristics of intersectional strata were most important regarding depressive symptoms?

Method

Analyzes were based on the data from the baseline survey of the NAKO Health Study (N=204,878). Migration background (own country of birth and nationality; parents' country of birth), age, gender and education (classification according to ISCED-97) were used as inequality indicators, which made up the intersectional strata. Depressive symptoms were assessed using the depression module of the Patient Health Questionnaire (PHQ-9) and included in the analyzes as a bivariate outcome (PHQ-9 score ≥ 10 indicating depressive symptoms). In the context of the MAIHDA framework, a multilevel binary logistic regression model was calculated to analyze the intersections. This approach allowed examining differences between the intersections, their connection with depressive symptoms and the importance of individual intersection characteristics. Adjusted predicted probabilities ("marginal effects") were calculated to determine the risk of depressive symptoms for each

intersectional strata, and the variation between those groups. The analyzes were carried out in four steps: 1) Calculation of the explained variance of the outcome by intersectional strata. 2) Determine variation regarding the outcome between the intersectional strata. 3) Contribution of the different intersectional strata towards the explained variance (proportional change in the between-stratum variance, PCV). 4) Analysis of potential multiplicative effects.

Results

Depressive symptoms were more common among women, lower-educated groups and first-generation migrants. The most vulnerable group was first-generation migrants with a low level of education (predicted probability of depressive symptoms from 17% to 21%). The multi-level analysis showed that education contributes most to explaining the inequalities (PCV of 73.3%), while the explanatory contributions of gender and migration background were considerably smaller (PCVs of 18.7% and 6.9%, respectively). We found no multiplicative increase of risk for depressive symptoms when people were exposed to multiple risk characteristics simultaneously.

Discussion

The social gradient, measured based on singular inequality characteristics, would have concealed differentiated risk patterns that became visible through an intersectional perspective. It was thereby also possible to work out the importance of the inequality indicators. However, there was no evidence in our data of an interaction in terms of a multiplicative increase in risks when several dimensions of inequality were present at the same time. Our analysis and results suggest that this work can contribute to the theoretical and empirical discussion of intersectional approaches.

Socio-economic impact of the COVID-19 pandemic on Filipino migrant workers: A scoping review

Kristel May Gomez-Magdaraog (University of Geneva), Claudine Burton-Jeangros (University of Geneva), Yves Jackson (University of Geneva)

Abstract

Filipino migrant workers, known locally as Overseas Filipino Workers (OFWs), are considered *bagong bayani*, or modern-day heroes, as their remittances have a positive long-term impact on the Philippines economy. The Philippines ranked 10th worldwide in terms of net emigration from 2010 to 2020. The deployment of OFWs declined during the pandemic, and this was estimated to have adverse effects on remittances. As a migrant-sending country, the Philippine government had to deal with the mass of unemployed OFWs stranded in their host countries and organize large-scale repatriation of OFWs. This scoping review aims to assess the existing literature, identify research gaps, and propose future research directions concerning the socio-economic impact of the COVID-19 pandemic on OFWs and their left-behind families. The results indicate that the impact of the pandemic on OFWs was not uniform. It is evident that OFWs in precarious situations beforehand have become even more vulnerable. The loss of their source of income in the host country (such as the US, UK and Hong Kong) and the restrictions on international mobility during the pandemic had significant detrimental effects on their well-being and their families left behind, regardless of their income level or type of job. Upon returning to their home country, they often experienced anxiety, depression, discrimination, and difficulty in finding a job. Overall, this scoping review highlights the urgent need for greater recognition and protection of OFWs in times of crisis. It is crucial to address the systemic issues that contribute to their vulnerability and to ensure that they receive adequate support and protection in host countries and the country of origin.

Area-level differences in life-expectancy using a new Index of Multiple Deprivation in Sweden

Lode van der Velde (Karolinska Institute), Ahmed Nabil Shabaan (Karolinska Institute), Anna-Karin Danielsson (Karolinska Institute), Theo Bodin (Karolinska Institute), Terje A. Eikemo (Norwegian University of Science and Technology), Stefan Swartling Peterson (Karolinska Institute), Emilie E. Agardh (Karolinska Institute)

Introduction

A long tradition of studies investigating the effect of places on health has established the notion that where you live matters for health. Although the effect of individual level determinants of health is generally larger, place has consistently been found to shape people's health even after controlling for individual determinants. Moreover, it is in geographical places that multiple adversities often converge, creating so-called deprived areas. The inequalities in the burden of disease stemming from these disparities have been a major cause for public health policy and social interventions. In Sweden, epidemiological inquiries into social stratification of health are often limited to single or a small number of socio-economic exposures, such as education or income. However, to fully understand the complex pathways that lead to social differences in health at a population level and to set the stage for targeted interventions, a more thorough understanding of the deprivation states that lead to inequalities in ill-health is needed. We therefore propose the Index of Multiple Deprivation in Sweden (IMDIS), which aims to capture the multitude of explanatory factors for social differences in health and moves beyond the singular measures of socio-economic status. Furthermore, a growing body of evidence suggests that individuals living in deprived areas are at greater risk of early death. In this study, we therefore aim to assess the cumulative effect of these deprivation states on the burden of disease, measured by life expectancy.

Methodology

We developed a compositional index of multiple deprivation for small areas in Sweden (IMDIS) to identify the materialist explanations for differences in life expectancy. In doing so we concentrated on the multi-dimensional character of deprivation, focusing on both monetary and non-monetary features of poverty. Focusing on potential indicators with a proven gradient in health that are attuned to the Swedish context, fifteen variables across four domains (Housing, Employment, Income & Capital and Education) were selected, normalized and weighted into scores of multiple deprivation for each Demographic Statistical Area, or DeSO area. Within domain double counting has been limited by creating non-overlapping variables based primarily on age. Equal weights were applied to create the within domain indices, while the overall score was constructed using factor analysis to extract relevant weights between domains. The DeSO areas, each with an average population of 1646 people, are subsequently ranked and aggregated into higher administrative levels (municipal, region). In 2015, 5984 DeSO areas were ranked based on the aggregated deprivation scores, covering approximately 9.8 million individuals. Quintiles of deprivation were created based on this ranking. To highlight the interdependencies of indicators and domains in the index, cross-correlations were calculated using Spearman's Rho. Life expectancy was computed for each deprivation quintile using standard period life expectancy methods. To assess the relation between life expectancy and level of deprivation we apply a Poisson regression.

Results

The newly developed Index of Multiple Deprivation in Sweden underlined the strength of the association between all domains and emphasized the occurrence of multiple deprivation states in place and time. Using the IMDIS, our preliminary results indicate higher life expectancy at birth in the least deprived areas. In other words, life expectancy was lowest in those areas where people are faced with the largest accumulation of adversities.

Conclusion

We developed an index of multiple deprivation to capture the multi-dimensional nature of deprivation. In a first, it gives an up-to-date account of the distribution of deprivation across Sweden at the DeSO-level and accommodates the different pathways for social differences in health. Using the IMDIS, we found a distinct gradient between the level of deprivation and life expectancy. To improve population health, the health gap between those in deprived areas and those in more advantaged neighborhoods needs to be narrowed.

Labor, Work, Health and Inclusion, Thematic Session – Chair: Veerle Buffel – Room K.203

The impact of hermeneutical injustice on reporting sexual harassment in higher education

Anneleen De Cuyper (University of Antwerp), Sarah Van de Velde (University of Antwerp)

Abstract

Higher education is an industry known for its high prevalence of sexual harassment (Bondestam & Lundqvist, 2020; Kirkner & Mazar, 2018). Victims/survivors of such behavior not only risk immediate negative experience but also a long-term impact on their physical and mental health, such as increased anxiety, suicidal ideation, emotional exhaustion, sleeplessness, stress, substance use and depression (Barbier et al. 2023; van Roosmalen & McDaniel, 1999). Only a minority of victims/survivors, however, disclose the behavior to official university services (Amar et al. 2014; Spencer et al. 2017). Several reasons for this underreporting have been studied, including – and specifically relevant for the current research – the inability to conceptualize one’s own experience as sexual harassment (Jackson, 2019; Jenkins, 2016; Orchowksi et al. 2019). Yet, this inability is not limited to the victim/survivor themselves: Upon disclosure, they might also be confronted with a lack of understanding or an inability to convey their own experience in an intelligible manner to others (Fricker, 2007; Jackson, 2019; Medina, 2017). Following Fricker (2007), we believe both cases could be better understood by viewing it through the lens of *hermeneutical injustice*. Hermeneutical injustice is the injustice that arises when someone is unable to make their own experience intelligible to themselves or others due to hermeneutical marginalization and structural inequality (Fricker, 2007). In other words, one’s ‘ability to know’ is put into question because the concepts and social meanings needed to understand their experience are not part of the dominant and collective resources. Important to note, hermeneutical injustice is different from (but operates together with) *testimonial injustice*, which happens when one’s credibility is questioned by another because they belong to a marginalized and/or stigmatized group (Fricker, 2007). In short, whilst testimonial injustice touches upon the lack of *credibility* caused by the prejudices of another individual, hermeneutical injustice is about the lack of *intelligibility* caused by structural inequalities.

The setting of this study, a Belgian university, is specifically valuable for trying to get a better understanding of the existence and working of this latter concept. First, universities are often characterized by a patriarchal and bureaucratic structure that fails to fairly represent the voices of the groups most often confronted with sexual harassment (i.e. women and other minorities) (Bird, 2011; MacKinnon, 1979). Second, universities are knowledge institutions where one’s reputation, seniority and tenure are tightly intertwined with one’s academic accomplishments (Troiani & Dutson, 2021). Both issues point to the potential structural impact of universities on the limited contribution of people most likely to become victims of sexual harassment to the collective concepts and social meanings employed by the institution (and society in general). Therefore, the current study wishes to provide an answer to two research questions: (1) *How does hermeneutical injustice play a role in university members’ decision to not report sexual harassment to the relevant institutional services?*; (2) *(How) does hermeneutical injustice occur after reporting sexual harassment to the relevant institutional services?* Thus, we intend to research how different stakeholders perceive sexual harassment incidents after they took place.

To answer the first question, the Belgian sample of the Uni4Equity questionnaire dataset on sexual harassment in higher education was analyzed (N = 1403 for staff and N = 1786 for students). The respondents were asked whether they encountered certain situations at the university which the Uni4Equity project defined as sexual harassment. Preliminary results show that most of the respondents who were confronted with one or more of these situations (N = 303 for staff and N = 322 or students) did not disclose it to formal university or external services. The main reasons behind this lack of action were that the victim/survivor did not perceive the behavior to be serious enough to report and that they did not recognize the behavior to be violent at the time of occurrence. Additionally, when respondents were asked whether they have been confronted with sexual harassment at the university without providing any further clarification on what this term entails, significantly less people responded yes. While additional data analysis is necessary to provide further evidence, these preliminary findings could be interpreted as hermeneutical injustice demonstrated by the inability to perceive one’s own experience as sexual harassment.

In order to properly study the second research question, the quantitative data of the Uni4Equity questionnaire will be complemented by in-depth interviews with various university stakeholders who have been directly involved in sexual harassment cases at university. This data will improve our understanding of how hermeneutical injustice plays out during sexual harassment procedures at university. Moreover, the combined data will allow

us to provide recommendations to higher education institutions on how to identify hermeneutical injustice during sexual harassment procedures. Finally, the insights from this study will enable universities to limit the negative short- and long-term health and career consequences for victims/survivors.

Life course before and after receiving a temporary disability pension

Anu Polvinen (Finnish Centre for Pensions), Aart-Jan Riekhoff (Finnish Centre for Pensions)

Introduction

Postponing retirement and lengthening working careers are important social policy goals in many countries. However, a significant number of working-age individuals leave the labor market prematurely due to health problems or disability. In Finland, approximately 20,000 people retire on a disability pension each year, with half of them being granted a temporary disability pension with the aim of returning to work. It is relative uncommon for individuals to find employment after receiving a temporary disability pension, and many continue to receive a permanent disability pension over time.

Several individual-level factors are known to be associated with disability retirement, but little is known about how these factors are related to the life course after temporary disability retirement, such as returning to work or experiencing unemployment. The objective of this study is to examine various work, retirement, and unemployment patterns after temporary disability pension. Furthermore, we will describe these patterns based on individual-level factors and investigate the development of income (such as earned income, sickness or unemployment benefits) before and after receiving temporary disability pension.

Methodology

Individuals aged 30-54 who were granted a temporary disability pension in 2016 were followed for five years before and after their retirement using total register data from Statistics Finland and the Finnish Centre for Pensions. A sequence analysis was conducted to identify typical life course patterns following temporary disability pension. Additionally, we describe the association between individual-level factors and the observed patterns, as well as the development of incomes within these patterns between years 2011 to 2021.

Results

Preliminary results yielded a six-cluster solution through sequence and cluster analysis. The results suggest that just under a fifth of those who received a temporary disability pension were able to return to work on a reasonably permanent basis. More than half continued to receive a disability pension, either full or partial, throughout the follow-up period. In addition, some received a full disability pension for a period of 1-3 years, after which they appeared to experience short periods of disability, unemployment or employment. After receiving a temporary disability pension, fewer than 20% of recipients received unemployment or other benefits shortly after retirement.

Significant differences were observed between the clusters. Female gender and higher education was associated with higher likelihood of returning to work or receiving a partial disability pension several years. Those who ended up to receive full disability pension or unemployed benefits were more often men and relatively low educated. Higher income was associated with employment after receiving a temporary disability pension or receiving a partial disability pension. This is partly income received from work. Also, individuals who continued to work had more stable careers and higher incomes prior to retirement. Those who ended up on receiving permanent full disability or becoming unemployed received more sickness or unemployment benefits prior to retirement.

Conclusions

We identified several distinct clusters of individuals who either returned to work, retired, or became unemployed following a temporary disability pension. These clusters differed significantly in many individual and income

factors. Our results suggest that many individual-level factors and life events before retirement are associated with the life course following temporary disability pension.

Healthcare workforce diversity in the context of violent conflict

Ariela Popper-Giveon (David Yellin College of Education), Yael Keshet (Western Galilee College)

Abstract

There is growing diversity in organizations, and the benefits of inclusive climates are gaining recognition. However, diversity is still much more easily achieved than inclusion. The optimal distinctiveness theory (ODT), which designates both belongingness and uniqueness, can be implemented as a framework for organizations that aspire to increase inclusion. In Israel, it is interesting to examine the experiences of Arab healthcare workers, who are members of an ethno-national minority group, in the context of a violent conflict. The complex situation prevailing in Israeli public hospitals, which employ both Jewish majority and Arab minority healthcare professionals, has escalated since the outbreak of the war in Gaza. We will analyze recent case studies that exemplify this tension. The cases reveal that Arab workers experience both belongingness and uniqueness. The former is reinforced by values of humanism and professionalism. However, regarding the latter, while their cultural and religious uniqueness is respected, their political opinions on the Israeli–Palestinian conflict are silenced and even persecuted. ODT may contribute to our understanding of how to achieve the inclusion of minority group workers in healthcare organizations comprising both belongingness and uniqueness, particularly in conflictual contexts.

Mental health consequences of poor-quality employment in Germany: the role of work/family value orientations

Deborah De Moortel (Free University of Brussels), Rebeka Balogh (University of Warwick), Miriam Engels (Open University of the Netherlands), Julie Vanderleyden (Free University of Brussels)

Background

Poor employment quality (EQ) has been shown to be associated with poor mental health, yet most studies show cross-sectional associations, and few studies report gender-specific associations or examine the underlying pathways between poor EQ and mental health. Using a large representative German panel dataset, we first investigate the different employment quality (EQ) constellation in Germany, we then link these clusters to a reduction in mental health two-years later for men and women separately. Moreover, we investigate an underexplored pathway between EQ and mental health. Drawing on the Person-Environment (P-E) Fit theory, it can be expected that a mismatch between one's values and one's employment model might exacerbate the relation between poor-quality employment and poor mental health.

Objective

EQ clusters are built and linked to mental health two-year later and it is tested whether this relation is moderated by work and family value orientations for men and women separately.

Methods

Using the German Socio-Economic Panel 2016 to 2018, we built EQ cluster using Latent Class Cluster Analyzes, and, using conditional change models, we linked the probabilities of the EQ clusters to a change in mental health two years later. We test the P-E Fit theory, assessing interactions between EQ clusters and work values (i.e., importance of success at work) and family values (i.e., importance of having children), respectively.

Results

We found six EQ clusters: SER-like, precarious unsustainable, precarious full-time, SER-light, portfolio and

protected part-time employment. Controlled for socio-demographic characteristics, precarious unsustainable employment for men and precarious full-time employment for women is linked to a deterioration in mental health after two years. Portfolio employment is linked to an improvement in mental health in men. The interaction models yield evidence for adverse mental health consequences of a P-E misfit for high work- and family-centered men in protected part-time employment, and for high work-centered men in precarious unsustainable employment. High family-centered men in SER-like jobs also experience a deterioration in mental health two-years later.

Conclusion

This study found evidence that poor employment quality is related to a reduction in mental health in the long term. Moreover, our study suggests that psychological pathways (such as the P-E misfit) is an important contributor to a deterioration in mental health for male precarious workers, but not for female.

Loss of income in women of midlife age in the Netherlands: An intersectionality-informed quantitative analysis

Maaïke Muntinga (Amsterdam UMC), Irene van Valkengoed (Amsterdam UMC), Petra Verdonk (Amsterdam UMC), Henrike Galenkamp (Amsterdam UMC), Eric Moll van Charante (Amsterdam UMC), Karen Nieuwenhuijsen (Amsterdam UMC)

Introduction

In the Netherlands, gender differences in both access to paid work and income continue to exist. Midlife women are more likely than midlife men to experience a loss of income from paid work: they more often reduce their work hours, or exit the labor market all together. Although equitable access to paid employment is important to reduce social and health-related inequalities, little is known about which factors contribute to a loss of income among midlife women in the Netherlands. Our aim was to explore social and work-related determinants of loss of income in a population of women of midlife age (45-60 years old) of different ethnic backgrounds in the Netherlands.

Methodology

We took an intersectionality-informed approach. Baseline data from the HEalthy Life in an Urban Setting (HELIUS) study were linked with individual-level data from Statistics Netherlands. 2 551 women were included. Loss of income was defined as a reduction in personal income by at least five percent over five years follow-up. We first tested multivariate models. Variables significantly associated with loss of income were then used to test multiplicative interactions.

Results

The percentage of loss of income in our sample ranged from 25 percent (Surinamese-other group) to 43 percent (Turkish group) between the various ethnic groups. Compared to the native Dutch group, Turkish women were significantly more likely to experience loss of income (OR 1.76). Inclusion of interaction terms in the model did not change estimates for the differences in the odds of loss of income between the ethnic groups.

Conclusion

Gendered, ableist and classed factors produce work environments that push midlife women out of the labor market. For Turkish women, ethnicized marginalization might play a role in Turkish women's being most likely to experience loss of income in midlife, which might further exacerbate existing inequalities. Loss of income might reflect socioeconomic privilege when midlife women who can afford it reduce their work hours to protect themselves from the health impact of inequitable workplaces. Further research should disentangle the complexities of loss of income among midlife women, and investigate which women are particularly marginalized in the Dutch labor market. This requires that existing and future cohorts include intersectional methodologies and variables, preferably in a pre-collection phase of the research.

4 July: 13:00 – 14:00

Scientific Poster Presentations - Foyer

4 July: 14:00 – 15:00

Discussing the Publication Landscape – Chairs: Sarah Van de Velde & Stéphane Cullati - Room K.001

Scientific publishing is an almost unique area of commercial activity. It concerns a small sub-group of the population (the scientific community) but its turnover (\$£19 billion) rivals the recording and film industries in size, and its profitability, with a margin around 36%, exceeds even the technology giants like Apple or Google. The economic model of scientific publishing, as highlighted in a Deutsch Bank report, is characterized by the “triple pay” principle, where the State funds research, pays the reviewers and editors who control the quality of research, and subsequently buys back the publications.

As far as scientists are concerned, they are all aware that their careers depend on the funding they obtain and the success of their publications, and that it is important to publish their work in journals with high credibility and reputation. Yet, there was historically less emphasis on immediate publication, allowing for a more iterative research process: scientists could work slowly, tinkering, going backwards, reworking, correcting, until perhaps one day publishing. Today, scientific publishing is faces challenges such as the publishing pandemic, peer-reviewer crisis, the proliferations of rogue actors (predatory journals, pirate publishers and fake reviewers), and the evolving landscape of Open access.

Editors from health sociology journals and those publishing health sociology research will convene in a round table to address these pressing issues.

Participants to the round table

- Terje Eikemo, Chief Editor of *Scandinavian Journal of Public Health*
- Karen Lowton, Editor-in-chief of *Sociology of Health and Illness*
- Hannah Bradby, Specialty Chief Editor of *Frontiers in Sociology* / *Medical Sociology*
- Olaf von dem Knesebeck, Editor-in-chief of *International Journal of Public Health*
- Ellen Annandale, Chair of the Trustees of the Foundation for the Sociology of Health and Illness

4 July: 15:30 – 17:00

Public Health and Prevention, Regular Session – Chair: Ana Patricia Hilário – Room K.101

Laminated system and participation: Sociological theoretical suggestions on antimicrobial resistance through an intersectional approach

Angela Genova (University of Urbino Carlo B)

Abstract

This proposal is concerned with supporting the theoretical background to investigate Antimicrobial resistance (AMR) within One Health approach through a sociological perspective. To explore the impact of intersectionality to antibiotic resistance exposure and transmission, researchers face several challenges. This study discusses the potentiality and limits in applying Bhaskar's interdisciplinarity approach (2010) to the area of AMR research, both at ontological and epistemological level.

From the ontological dimension, AMR, as almost all the phenomena, occur in open systems. Therefore it is generated not by one, but a multiplicity of causal structures, mechanisms, processes or fields. There is the need to understand the co-existence of several mechanisms producing a novel result as AMR. To understand the complexity of AMR we suggest embodying Baskar's laminated system proposal: where several levels interacting or coalescing in the totality. A first step in this perspective would be to investigate the "multi-mechanismicity" (Baskar, 2010, p.4) and therefore number and typology of levels that may be involved in any particular explanation, aware that there is no a priori account of such levels and being open to intercepting new levels. The second moment would be of redescription: concerning the appropriate level of description of the component cause between abstractness and concretion. Therefore applying Baskar's proposal (2010, p.6), AMR may be considered as 1) instantiating (transfactual universal laws), but at the same time 2) constituted by particular specific mediations which differentiate it from others of its kind (for example, AMR may concern different human being as well as animals). Moreover, each instance of such a differentiated universal will be characterised by 3) a specific geo-historical trajectory. This will further particularise it from others of its kind; and each such geo-historically specific and mediated instance of a universal will also be irreducibly unique. Nevertheless, the different components of a complex phenomenon are suggested to be analysed holistically: as components of the whole of which they are component. According to this perspective, events as AMR may be considered as nexus and the related structures as system, while internal and external relationality affects the holistic causality, characterised by inner complexity and outer complexity (considered as context influencing or shaping, instead of generating or determining the event). The laminated system approach aims to avoid reductionism. Within this framework, agency and collectivity may be distinguished in seven levels:

- the sub-individual psychological level
- the individual or biographical level
- the micro- level investigated by ethnomethodologists and others
- the meso-level focusing on relations between functional roles (such as capitalist and worker or member of parliament and citizen)
- the macro-level investigating the functioning of whole societies or their regions (such as the Italian economy)
- the mega-level of the analysis of whole traditions and civilizations
- the planetary-level related to cosmos ad a whole

All these levels contribute in constituting the laminated system.

To investigate AMR as part of One Health perspective would need to consider the intrication of several distinct explanatory mechanisms, operating at different levels of reality, overcoming a mono disciplinary approach of the phenomena, promoting a developing integrative pluralism (Bhaskar, 2010, p. 11) to grasp and comprehend the ontological complexity of AMR. Developing the sociological theoretical perspective side by side to the biomedical dominant approach in One Health would suggest to consider at least three different social dimensions: material, institutional and cultural. Understanding antimicrobial resistance through an intersectional approach, in fact, could benefit by also considering that social beings are constituted in part by discourses (related to cultural dimension), related to oppressive power relations. Considering such dimensions would suggest to further investigate relationships not only between different disciplines but also between different professions and social roles.

Moreover, from the epistemological perspective, applying intersectionality to the One Health approach to AMR calls for the capacity of different research teams from different disciplinary areas to communicate effectively with each other in “cross-disciplinary understanding” (Baskar, 2010, p.5). To develop a creative transdisciplinary in dealing with intersectionality to AMR a new form of education and socialisation would be required to research workers, who have mainly educated within orthodox monodisciplinary context, in line with Baskar (2010) analysis applied to another complex theme as climate change. To face this epistemological challenge a participatory social science research would open the way to build up a shared understanding. Participation in the shared research approach would mean active involvement of different researchers from different disciplines fostering interprofessional cooperation, but also active involvement of citizens taking on board the intersectionality perspective, to valorize the lay knowledge also based on community of practices.

This study aims at developing the scientific debate on theoretical perspective in AMR within the One Health approach suggesting to use the concept of “laminated system” to ontologically underpin the critique to the biomedical reductionism approach to AMR. According to this ontological perspective, this study suggests the use of shared research within a participatory approach to develop an effective approach in AMR studies within One Health debate.

The organization of the primary healthcare system and vaccine attitudes: A comparative European study

Esther Lermytte (Ghent University), Piet Bracke (Ghent University), Katrijn Delaruelle (Ghent University)

Introduction

Routine prophylactic childhood immunizations are considered as one of the most crucial preventive health interventions, as it has caused substantial falls in the morbidity and mortality of various diseases, both protecting individuals and contributing to herd immunity. While vaccination services are widely available in the European region, vaccination programs are challenged with people who choose to delay or refuse vaccination (Larson et al., 2016; MacDonald, 2015). This phenomenon, referred to as vaccine hesitancy (VH) is defined by the WHO (2022, p. vii) as “a motivational state of being conflicted about, or opposed to, getting vaccinated; including intentions and willingness”. VH is increasingly recognized as a worldwide public health concern. While the sociodemographic differences in vaccine hesitancy are well documented, the literature lacks in acknowledging the contextual factors that can affect vaccine hesitancy (Dubé et al., 2021; Vulpe & Rughiniş, 2021). Nevertheless, previous research found large variation across Europe in the utilization of other preventive care services, highlighting the impact of contextual factors (Jolidon et al., 2021; Jusot et al., 2012). As such, characteristics of healthcare systems have been associated with either the success or failure of preventive programs across Europe (Jusot et al., 2012). More specifically, the strength of primary care is related to better population health (Kringos et al., 2013; Starfield et al., 2005). Furthermore, it should be considered how such macro-level determinants interact with individual-level characteristics and might affect certain socio-demographic groups more than others. As the link between healthcare system characteristics and vaccine attitudes remains understudied, we aim to add to the existing literature by addressing the following research questions:

1. How are healthcare system characteristics, particularly related to primary care, associated with people’s attitudes towards vaccines?
2. Do healthcare system characteristics have a differential impact on the perceptions of vaccines for specific socio-demographic groups?

Methodology

This study examines the association between healthcare system characteristics and vaccine attitudes, taking into account that these macro-level determinants interact with individual-level characteristics and might affect certain socio-demographic groups more than others. Hence, multivariate multilevel analyzes with cross-level interaction effects will be conducted. To this end, we will rely on data from the Vaccine Confidence Project for

the operationalization of the variables related to vaccine attitudes and vaccine hesitancy. We combine this dataset with macro-level indicators for the operationalization of the variables related to healthcare system characteristics, retrieved from various datasets such as the OECD Health Data, Eurostat and the World Health Organization database.

Results

We hypothesize that (i) certain healthcare system characteristics are associated with positive vaccine attitudes, (ii) countries with stronger primary care are associated with less vaccine hesitancy, (iii) there are existing differences in vaccine hesitancy between sociodemographic groups (age, gender, income and education) that are affected by healthcare system characteristics and lastly that, (iv) healthcare systems with stronger primary care can reduce inequalities between sociodemographic groups.

Conclusion

This study offers new comparative insights into variations in vaccine attitudes and vaccine hesitancy among various socio-demographic groups and across Europe. Utilization of this cross-country data set allowed us to explore, via multilevel analysis, the association between vaccine attitudes and healthcare system characteristics, specifically related to primary care. Our study suggests that there are significant associations between some healthcare system characteristics with regard to the strength of the primary care system and people's vaccine attitudes and that certain contextual conditions have a differential impact on specific socio-demographic groups.

Navigating antimicrobial resistance in Canada: Unveiling perspectives of experts and the lay public

Eve Dubé (Laval University), Antoine Garnier (Centre de recherche du CHU de Québec-Université Laval)

Background

It is estimated that 15 Canadians per day are losing their lives to antimicrobial-resistant (AMR) infections, with growing burden as resistance rates for all priority organisms are increasing. The 2023 Pan-Canadian Action Plan on AMR uses a One-Health approach and proposes 10 priority interventions to fight against AMR (e.g., develop guidelines for appropriate use of antimicrobials; implement educational guidelines for healthcare providers; foster understanding of the risks of AMR amongst the public, patients and producers). It also stipulates that interventions should adopt an equity lens and include measures for population groups that face the greatest risks to AMR. In this presentation, we will discuss findings of two explorative projects conducted in Canada to better understand the challenges in the fight against AMR.

Methods

In 2021-22, we conducted interviews with 59 Canadian experts in AMR (e.g., microbiologists, lab scientists, public health practitioners) working in government, public health institutions or in the pharmaceutical industry. In 2019, we conducted a web-based survey among a representative sample of 7,259 Quebecers to assess their knowledge, perceived risks, and attitudes towards AMR as well as antimicrobial consumption. Findings of these two projects were analyzed using an "equity lens" consistent with an intersectional perspective. The potential impact of different factors (e.g., gender/sex, place of residence race, ethnicity, culture, language, occupation, age) on participants' views and behaviors with regards to AMR were assessed.

Findings

Key challenges identified in interviews with experts were: AMR is politically underprioritized, surveillance is suboptimal, the One Health approach is not yet well established, and stewardship programs are underfunded and uncoordinated. The negative impact of the COVID-19 pandemic on surveillance and stewardship resources dedicated to the fight against AMR was noted. Experts also mentioned the disparate epidemiology of AMR pathogens across the country which limit implementation of national approaches. Furthermore, the lack of a national approach in AMR surveillance, due to jurisdictional issues between the federal and provincial

governments, does not allow to identify population groups most at-risk based on socio-economic characteristics, which limits implementation of strategies to tackle inequities.

Findings of the survey indicated that while most participants were aware of AMR, only a minority had modified their behaviors with regards to antimicrobials. Perceived risk of AMR was generally low, with participants living below the poverty line and those with low level of education having even lower risk perceptions. These participants were also less likely to report feeling capable to prevent AMR. Travelers, parents of young children and participants living below the poverty line were more likely to report inadequate use of antimicrobials (e.g., stopping before end of treatment).

Conclusions

To conclude, while all Canadians are at-risk of AMR infections, our analysis revealed differences in knowledge, antimicrobials use and perceived risk between people with different socioeconomic background. Experts noted the gaps in our understanding of groups most vulnerable to AMR. Given the multifaceted nature of AMR, effectively implementing interventions to address AMR will require a holistic and inclusive approach, considering the interconnectedness of political, healthcare, and societal factors.

Health, Disease, and Health Sociology

Galya Chamova (Trakia University), Georgi Sarov (Trakia University)

Introduction

In various scientific disciplines, defining the subject of study can be a challenging task. Medicine, for instance, continues to use terms health and disease without providing clear, universally accepted definitions. Several proposals attempt to capture the essence of health, such as the absence of disease (Boorse, 1977, 2014), internal ability to achieve vital goals (Nordenfelt, 1987), complete physical, mental, and social well-being (World Health Organization [WHO], 2006), and the ability to adapt and self-manage (Huber et al., 2011). Despite these reasonable proposals, a consensus on a common general health concept remains elusive (Haverkamp et al., 2018).

Method

Employing content analysis, we sought a common understanding in the context of various texts. To avoid dichotomous definitions, we try to put health and disease in one class and to find how they differentiate. Additionally, we incorporated pathophysiological explanation of “disease”, psychological explanation of “illness” and sociological explanation of “sickness”.

Results

All definitions suggest in the context an intuitive understanding that health represents a normal state, while disease signifies an abnormal state of an individual, but do not imply understanding that person is a complex four-dimensional structure, consisting of body, psyche, roles, and a self-concept (Sarov, 2022a, 2022b). Boorse stresses on biology, Nordenfelt – on roles and self-concept, Huber – on psychological context. The WHO's definition is sensitive to all aspects but lacks clarity and practical utility.

Both health and disease represent states of the body, but there is a third state too. For example, shortly after receiving a meal blood sample shows the values as in metabolic disorders – this is a risk condition. All day we are challenged by different risk factors that induce risky conditions. We remain healthy only because compensatory capacity consistently restoring our internal authenticity. Normality is secured by compensatory capacity.

From pathophysiological viewpoint (Sarov 2022b, 2022 c, 2022d) disease is a process initiated with a primary affect caused by pathogens. Initial affect triggers consequent pathological process. In acute diseases, the primary affect becomes apparent right from the outset. Conversely, in chronic diseases, a prolonged latent phase ensues,

during which the pathological process utilizes compensatory capacity without disrupting daily life. Importantly, during this phase, there is no subjective discomfort, and the patients believe that they are in good health. This mix of experiences contributes to different terms of pathological states: disorder, disease, illness, and sickness. 1) Disease is an abstract scientific concept about a specific pathological process and its clinical signs. It serves as a theoretical construct that may not have occurred in practice in its entirety. Nonetheless, it provides physicians with a framework to categorize abnormal states in the process of diagnosis; 2) "Disorder" is a pathological state that does not progress in pathologic process. It manifests with constant subjective discomfort and limited social activity. 3) Illness is a dynamic pathological condition that incorporates biological changes and psychological experiences. Biological changes are discovered in medical examinations and psychological experiences cause subjective suffering, asking for medical help and limiting social activity. In results, person agrees to be treated as a patient. Initial stages of illness usually are unspecific feelings of discomfort; 4) For others and society individual illness is a social incident. Sickness is the social interpretation of medical states, needed for institutionalizing ill individuals. Sickness (weak, moderate, heavy) depends on disease logic and personal condition. When illness does not distort social functioning there is no sickness.

Conclusion

Based on the considerations outlined above, we can draw the following role interaction: medical scientist creates notion about pathological conditions as a specific disease, patient suffers from illness that physician aims to categorize as disease, society interprets diagnosis and patient conditions as sickness and provides respective social support. These role interactions and institutional support are the subject of medical sociology (Sarav, 2022a). Health sociology is designated to study personal responsibility of individuals in everyday risks and to promote healthy lifestyle. Subjective discomfort should be discussed as possible primary affect of impending disease and risky lifestyle should be regularly tested with provocative tests for progressive reduction of the compensatory potential. In this case individual should be categorized as chronically ill and main efforts should be applied on intensive risk reduction, including social risks. Clinically ill individuals become patients and are expected to play this role according to medical instructions. Health should be understood in two ways: as ideal (authentic) state that compensatory mechanisms aim continuously (theoretical) and as enough compensatory capacity for maintaining resistance against pathogens (practical).

Surviving stomach bugs in UK ethnic groups: A qualitative study.

Iram Zahair (National Institute for Health and Care Research; University of Liverpool), Stephen Clayton (University of Liverpool), Ben Barr (University of Liverpool)

Background

The exposure patterns across ethnic groups are unclear for stomach bugs that cause self-limiting symptoms, significantly burdening UK healthcare services and the economy. This study seeks to fill this gap by exploring how inequalities arise in managing stomach bugs in UK ethnic groups.

Methods

A qualitative study using semi-structured interviews was undertaken. Ethical approval was given by the University of Liverpool (ref 10773), and data were collected by IZ over 11 months from 26th July 2022 to 26th May 2023. Purposive sampling was used to recruit a general UK population sample (excluding healthcare professionals) who were adults, partners, and parents from an ethnic minority group with recent diarrhea, vomiting or a stomach bug over the past six months. Recruitment was conducted through community gatekeepers using flyers. Participants were interviewed in person or virtually and gave written informed consent. An Amazon voucher incentive of £10 was imbursemented to participants for their time. Interviews were audio-recorded using a password-protected digital recorder, transcribed verbatim and analyzed using reflexive thematic analysis.

Findings

39 interviews were conducted with participants of Black (n =22), Pakistani (n = 9), Bangladeshi (n = 2), Indian (n

= 4) and Arab ethnicity (n = 1) and Maldivian (n = 1) ethnicity. This enabled an exploration of within-ethnic group experiences of stomach bugs in participants who self-defined their age, sex and ethnicity. Themes such as managing food preparation (n = 32), travel abroad (n = 11), personal cleanliness in the household (n = 9), school settings (n = 5) and work-induced or personal circumstances stress (n = 3) were consistently reported and overlapped across transcripts. The findings corroborate existing literature that there are more similarities than divergences in the management of stomach bugs across ethnic groups, like the burden of care disproportionately affecting women and using over-the-counter medication to manage symptoms.

Interpretation

We do not know if the impact of these experiences across ethnic groups is entirely representative of the broader ethnic categories (i.e. Asian vs Indian, Pakistani, and Bangladeshi), they belong to or if there are inequalities in their impact on ethnic groups living in different circumstances (i.e. UK born vs migrant).

Funding: This study is funded by the National Institute for Health Research (NIHR) Health Protection Research Unit in Gastrointestinal Infections, a partnership between Public Health England, the University of Liverpool and Warwick. IZ is a PhD student, and the views expressed are those of the author(s) and not necessarily those of the NIHR.

Contributors: SC and BB helped modify the topic guide. IZ conducted the interviews with input from BB and SC. All authors have seen and approved the final version of the Abstract for publication.

Healthcare Workforce , Regular Session – Chair: Veerle Buffel – Room K.102

‘Do I matter?’ Autoethnography as a method to promote inclusion in health

Ana Baptista (Imperial College London)

What is autoethnography and why is it relevant?

Autoethnography is a qualitative research anchored in personal and reflective ways of looking at lived experiences while simultaneously describing and above all critiquing cultural beliefs, practices, experiences, theories: “When we do autoethnography, we look inward – into our identities, thoughts, feelings and experiences – and outward – into our relationships, communities and cultures” (Holman Jones et al., 2016, p.46).

Recognising the limits of the positivist paradigm, autoethnography emerged as a method that recognises the limits of ‘objective’ scientific knowledge particularly regarding identities, lives, experiences, etc. This is thus a research method that increases the visibility of individual, nuanced, complex and usually unheard stories, while “offering a novel avenue to engage in reflexivity” (Koopman et al., 2020, p.2).

Autoethnography allows a creative and multimodal approach to share inner worlds of experiences, thoughts and emotions, focusing the attention on more or less scrutinised or even marginalised stories. Accessing more than one (single) reflexive narrative about lived experiences opens up possibilities to access diverse truths, frequently deep and rich in details (also called thick descriptions) (Grant, 2019), as well as “otherwise inaccessible private human experiences” (Koopman et al., 2020, p.2). Strong personal experiences are research resources that need, however, to be connected with cultural, social, political, educational beliefs, practices, experiences and theories.

Autoethnography is thus a way to connect with subjectivities and authentic voices, enhancing the process of understanding human complexity(ies) across different disciplines and exploring diverse themes. It thus presents itself with great potential to accessing different emergent narratives from Health practitioners navigating

different terrains and experiences, both “increasing the understanding and visibility of subjective experiences and the commonality of human experience” (Peterson, 2015, p.231).

In conjunction with other research methods, autoethnographic accounts have the potential to disclose complex educational and professional phenomena, anchored in diverse personal, professional, social and historical contexts (O’Connor, 2011). Participants’ autoethnographic, evidence-based accounts give investigators/academics/teachers/colleagues access to transformational, developmental and reflexive experiences.

Summary of the study and preliminary results

A scoping review (Arksey & O’Malley, 2005; Munn et al., 2018) is being conducted. Web of science and scopus have been used as databases. An inductive meta-analysis is being undertaken on published papers that have been co-authored by medical students who explored their educational experiences while at medical school.

We will present emerging themes on which the collaborative autoethnographic studies have been drawn, and discuss the implications of the following: 1) foci of collaborative autoethnographic papers, namely their similarities and differences regarding different educational journeys, through medical students’ eyes; 2) impact of the autoethnographic approach on medical students’ awareness, sense making of and transformational learning about their own experiences; and 3) emotional load explored by the medical students related to their own lived experiences.

The analysis above will be the stepping stone to discuss how inclusion can be considered an underpinning concept and element of praxis when engaging in (collaborative) autoethnographic studies.

Brief take-home messages

- 1) Autoethnography works with/from insider and more authentic knowledge, thus disrupting some ‘norms’ of research practice and enabling actionable reflexive loops that will impact on praxis.
- 2) Autoethnography creates a more equitable space for diverse narratives to be discussed and shared, reaching different audiences.
- 3) Autoethnography promotes in medical students an inquisitive attitude that positively impacts on their reflexive and other skills that will be of relevance for the future practice once they graduate.
- 4) Collaborative autoethnographic studies led by medical students open space for acknowledging diversity and using it proactively to enhance practice, in order to reach for more inclusive and equitable experiences.
- 5) (Collaborative) Autoethnography highlights the importance of often unused – but powerful – evidence to change educational cultures in multiple contexts.

Magic, mercifulness, relatedness, and paradoxical revelations: Qualitative evaluation of social work and health care professionals’ experiences of reading and writing groups

Elina Renko (The University of Helsinki), Jussi Valtonen (The University of the Arts Helsinki)

Introduction

Because the arts and humanities focus on lived experience and the interpretive processes required for human meaning making, they are thought to provide distinctive ways of understanding that are not achievable through biomedicine or other natural sciences. Reading, writing, and other arts and humanities are valued in medical education for fostering communication skills, perspective taking, personal insight, social advocacy, enhancing patient experience, improving population health, reducing costs, and promoting clinician well-being. We

organized a 7-week course, focused on close reading of fiction, poetry, and reflective writing, aimed to foster narrative competence in health care and social work professionals. We investigated (1) the participants' experiences of the effects of the course, and (2) perceptions of the relevance of the course content for clinical practice after the course. Our aim was to complement the findings from previous studies with a qualitative understanding of the range of experiences that reading literary fiction, personal writing and shared discussion can have in a group-based setting.

Methodology

We conducted individual semi-structured interviews (n=14). All data were analyzed using an inductive reflexive thematic analysis to guide the systematical interpretation of patterns of meaning in the dataset. Themes are analytic entities – i.e., patterns of shared meaning clustered around a central organizing concept – produced by the researcher and developed through analysis. Each theme is intended to capture a common, recurring pattern across a dataset.

Results

We generated five themes from the interviews describing the perceived effects of the course and the relevance of narrative skills. Each theme was centered around a key organizing idea. The first captures an overarching *qualitative experience* of the course process, namely that group work with close reading and reflective writing (1) involved an experience of unexpectedness that transcended everyday routines. The participants described the effects of the course as something that was difficult to put into words. To explain their experiences, the interviewees used figurative language and metaphors, including those depicting unexpected feelings of seeing or experiencing things in ways that surpassed or transcended perceptions and emotions they typically had in daily life. The other four themes focus on *the content* of what participants felt they gained from the course, namely that participating was felt (2) to engender a merciful attitude towards oneself and others; (3) to strengthen listening, self-reflection, and self-disclosure skills; (4) to transform relationships; and (5) to inspire reflections on professional and existential selves that often produced paradoxical insights regarding the participants' work in relation to humanity and patient-centered ideals.

Conclusion

Experiences of participation invited profound ethical and professional self-reflection, experienced transformation of relationships, reconsideration of professional and personal identities, new understandings of the meaning of work as well as reconsiderations of skills required for successful and ethical practice. The study was conducted in the cultural context of Northern Europe, Finland. In Finland, the value of the literary arts has not been widely discussed in healthcare or social work, and there are few examples of courses that integrate the literary arts in this context. We suggest that the shared space of the reflective writing course formed a creative and dialogical environment that enabled the effects that the participants describe. The results show how our individual experiences are deeply intertwined with social worlds, cultural and professional values, as well as with the overall character and atmosphere of the reflective writing process. We discuss the rationale and benefits of reading and writing groups aiming to encourage reflective skills in professionals.

Discrimination, disadvantage and disempowerment during COVID-19: A qualitative analysis of the experiences of a diverse healthcare workforce in the United Kingdom

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Introduction

Individual healthcare workers (HCWs) have faced many challenges arising out of their social locations and identities during the COVID-19 pandemic. The evidence base often describes these challenges (e.g., lack of appropriate PPE, redeployment, understaffing) in relation to inequities in how these have been experienced by HCWs based on individual characteristics such as ethnicity, gender or job role. In this paper, we examine how the intersection of multiple identity factors have impacted HCWs' experiences of challenges during the pandemic.

Methodology

As part of the United Kingdom Research study into Ethnicity and COVID-19 outcomes in Healthcare workers (UK-REACH Study), qualitative data were collected using interviews and focus groups, from 164 HCWs from different ethnicities, genders, job roles, migration statuses, and regions in the United Kingdom (UK) between December 2020 and July 2021. Recordings of the discussions were transcribed and a hybrid thematic analytical approach integrating inductive data-driven codes with deductive ones informed by an intersectional framework was adopted to analyse the transcripts.

Results

Three main themes identified regarding HCWs challenges were: disempowerment, disadvantage and discrimination. Our analysis also acknowledges that disadvantages faced by HCWs are at the micro, meso and macro ecosystemic levels. This merging of analysis which is grounded in intersectionality and considers the ecosystemic levels has been termed as 'intrasectorialism'.

Conclusion

The key themes of disempowerment, disadvantage, and discrimination illustrate the experiences of HCWs around the intersection of identity characteristics at multiple ecosystemic levels, and how they contributed to inequities and challenges during the pandemic. Whilst the UK-REACH Study did not utilise an intersectional conceptual framework in its original design, the diversity of the sample and the context of the study meant that applying an intersectional and related intrasectorial approach to analysing the data yielded novel and important findings. This study shows how intrasectorialism can help better understand how different forms of mutually reinforcing inequities exist at all levels for certain HCWs who face greater disadvantage, discrimination and disempowerment, particularly during the pandemic. This approach should inform future research and policy to meaningfully impact on health inequities in preparation for future crises.

Mismatched expectations and the rise in violence against doctors in India

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Introduction

Society grants medical professionals "status, respect, autonomy in practice, the privilege of self-regulation, and financial rewards on the expectation that physicians would be competent, altruistic, moral, and would address the health care needs of individual patients and society" (Cruess et al. 2004). These expectations that society has of the medical profession and these relational arrangements between them can be understood within the frame of a social contract (Welie, 2012). A well-functioning social contract and a harmonious relationship between the medical profession and the people it serves are essential for any country's health system to fulfill its mandate. In India, however, this social contract seems to be breaking down. In the last ten years, there has been a rise in violent attacks on doctors in India (Pai, 2015; Nagpal, 2017; Singh, 2017).

There is a vast body of literature on the doctor-patient relationship (e.g., Lipworth et al., 2013; Berger, 2014; 2018; Dunn, 2019), and within it there is some attention to patients' expectations (Cetin, et al, 2012). However,

there is less discussion on expectations healthcare providers have from society in the context of the broader social structures, institutions, and the health systems within which these expectations exist. In this paper we interrogate the (changing) nature and state of expectations within the social contract between the medical profession and society in India to make sense of the violent unraveling of this important social relationship.

Methodology

We present emerging findings from our qualitative study focused on understanding the rise in incidents of violence against doctors, conducted in India over eight months in 2022 and 2023. We conducted in-depth interviews with 25 purposively selected participants who have been involved (in varying degrees participated, associated, suffered) or witnessed or commented on any incidents of violence. Participants included doctors who had experienced violence, patients/patients' relatives who had resorted to violence, doctors' representatives, journalists, social commentators, lawyers who had represented doctors or those had resorted to violence, police who had investigated such incidents, and elected legislators of the local government. Analysis is ongoing, iterative, and involves repeated readings of interview transcripts, memos from fieldwork, and listening to interview recordings.

Findings

Our analysis reveals the disconnects and tensions in the expectations the medical profession and society have of each other about the organization and practices of the medical profession and how healthcare provision occurs. We found mismatched expectations and tensions around four overlapping axes: Communication related expectations and possibilities of outcomes; notions of profit-making and profiteering; nature and limits of medical treatment, and social identity. These mismatched expectations and tensions appear to be rooted as much in the more current context of market-logic based organization of healthcare in the country, as in the historical roots of expectations around these axes. They also serve as potential entry points to develop social policy interventions to help restore and recalibrate this important social relationship.

Conclusions

A systematic exploration of expectations as they stand now, the drivers of and reasons for changes to the 'expectations' of the parties involved, i.e., society (broadly and its various constituents) and the medical profession, can help to unpack better the rise in incidents of violence against doctors and the state of the social contract between the medical profession and society. The axes of mismatched expectations and tensions that our study reveals can serve as entry points to develop policy interventions to help restore and recalibrate this important social relationship.

Long-term care workers at the nexus of capitalist boundary struggles, an intersectional perspective

Saskia Duijs (Amsterdam UMC), Janine Schrijver (Independent photographer), Olivia Plak (Care worker in long-term care), Usha Jhingori (Care worker in long-term care), Yvonne Jaspers (Care worker in long-term care) Naziha Senoussi (Unpaid care worker in long-term care), Petra Verdonk (Amsterdam UMC)

Introduction

The health of paid care workers in long-term care is under pressure, but not for all care workers alike. Therefore, we need to address health inequities among paid care workers. This research focusses on the experiences of low-paid care workers in long-term care (elderly care). We aimed to understand their experiences from a critical gender and intersectional perspective. This study aimed to understand how care workers' lived experiences are structurally embedded and we fostered critical reflection on these structural inequities together with care workers.

Methodology

This participatory health research study includes qualitative and arts-based methods. The research team consisted of academic researchers, a professional photographer and long-term care workers who participated as

co-researchers in all phases of the research process. We first employed photovoice with 10 (un)paid care workers to set the research agenda. Second, we conducted qualitative interviews with experiences of women working as hired employees in LTC (N=27), with men working in long-term care (N=16), with self-employed care workers before (N=23) and during the COVID-19 pandemic (N=23). Interviews were mostly done by an academic researcher in duo with a co-researcher. Interviews focused on health experiences and health strategies. All studies were done from critical gender, diversity sensitive and intersectional perspective. Analysis of the findings was guided by intersectionality theory. We particularly used Fraser and Jaeggi's intersectional perspective on capitalism and their concept of boundary struggles in capitalism. We also employed arts-based analysis of the interviews using photography, resulting in a photodocumentary.

Results

Results address the gendered devaluation of care work in LTC, leading to poverty among paid care workers. Findings show that care workers are squeezed out of the organizations into self-employment due to growing informal caring responsibilities, menopause, poverty and racism. As self-employed care workers, women consequently have to negotiate their caring identity with an entrepreneurial identity, leading to material and health sacrifices to foreground a caring identity. Vis-à-vis, men working in long-term care can mobilize masculinity to obtain privileges such as larger contracts and higher salaries, yet masculinity backlashes in relation to health. Men opt out of care work due to health issues, which often remained hidden to colleagues and managers. For care workers of color, self-employment is a strategy to avoid racism in care organizations and thus to protect their health, yet they were most at risk for health and financial risks when the COVID-19 pandemic hit. We furthermore observed that self-employed care workers did not benefit from policy responses and for care workers of color additional challenges arose due to institutional racism in governmental organizations. Findings are translated into four portraits 'What You Don't See'.

Conclusion

We observed how long-term care workers find themselves at the nexus of boundary struggles in capitalism. Findings reflect boundary struggles between production and reproduction (a gendered boundary struggle), for example in the gendered devaluation of paid care work. Second, we observed a boundary struggle between economy and polity (a classed boundary struggle) as care workers were pushed out of the institutions of the welfare state into the free market as self-employed care workers, which led to moral tensions, health risks and exclusion from social security and policy responses to mitigate health and financial risks of care workers during the pandemic. Third, we observed a boundary struggle between exploitation/expropriation (a racialized boundary struggle), which manifested in experiences of racism. And between human and non-human nature, particularly in the COVID-19 pandemic. These boundary struggles trickle down into LTC organizations, shaping experiences in the workplace and become embodied in care workers' lives and health. Protecting, maintaining and repairing the health of paid care workers is not just an issue of care workers or employers. It is a societal issue and shaped by political choices.

Family Dynamics and Health, Regular Session – Chair: Sarah Van de Velde – Room K.103

(Not) again?! A second relationship dissolution: mental health and subjective financial situation

Kimberly Jacobs (University of Antwerp), Sarah Van de Velde (University of Antwerp), Dimitri Mortelmans (University of Antwerp)

Introduction

Modern relationships are increasingly characterized by temporary bonds rather than lifelong commitments, leading to multiple relationship break-ups throughout an individual's life (Amato, 2000; Cherlin, 2020). In the UK, the 2021 divorce rate stood at 9.3 for men and 9.4 for women per 1000 married individuals, with 20% of marriages ending before the 10-year mark (ONS, 2022). These statistics exclude cohabiting couples, whose relationships often face higher dissolution risks, especially in second or subsequent unions (Eickmeyer, 2019;

Beaujouan, 2016; Teachman, 2008). Break-ups have short-term negative impacts on mental health, but individuals typically recover over time (Leopold & Kalmijn, 2016). Thereby, going from dual to single-earner household changes the subjective financial status and as a consequence mental health. However, the long-term mental health impacts of subjective financial situation during multiple break-ups, particularly second break-ups, remain unclear. This study addresses this gap by examining the mental health consequences of the changing subjective financial status during the period of a first and second relationship dissolution, utilizing longitudinal data to capture these effects over time.

Methodology

Our study employs data from the UK Household Longitudinal Study (British Household Panel and Understanding Society), focusing on individuals who have experienced one or more relationship break-ups. The sample includes comprehensive relationship histories, sociodemographic information, and health variables collected over 28 waves from 1991 to 2018. We analyze the mental health outcomes associated with first and second break-ups, comparing these impacts and considering individual and break-up-related characteristics. The relationship dissolution includes marriages as well as cohabitations.

Results

Initial findings suggest that relationship dissolution is a complex process eliciting varied emotional responses. The first break-up often results in immediate relief from ongoing relational stress, particularly in cases of abusive or turbulent partnerships (Rognmo et al., 2013; Cavapozzi et al., 2020). However, it also introduces significant stressors, such as identity disruption and financial instability (Cohen et al., 2016; Vazard, 2022). While some individuals adapt and recover, others face chronic stress that extends into subsequent relationships (Amato, 2000; Hiyoshi et al., 2015). Repartnering, while beneficial for economic recovery, introduces new dynamics and stressors, often resulting in less stable second unions (Jensen et al., 2017; Bumpass & Raley, 2006).

The study further explores the economic impact of break-ups, highlighting that women, especially mothers, are more adversely affected financially than men (de Regt et al., 2012; Thielemans & Mortelmans, 2022). Financial hardship exacerbates mental health issues, creating a feedback loop where economic strain and poor mental health reinforce each other (Frankham et al., 2020; Hashmi et al., 2020). Successive break-ups appear to have a cumulative effect, where initial resilience diminishes, leading to greater mental health deterioration over time (Pearlin, 1989).

In conclusion, the literature review underscores the dual role of relationship dissolution as both a potential relief from ongoing relational stress and a significant source of new stressors, particularly financial. These findings emphasize the need for targeted mental health and financial support interventions to mitigate the negative impacts of relationship break-ups, especially for those experiencing multiple dissolutions. Further analysis will refine these insights, examining the nuanced differences in mental health trajectories following first and second break-ups and the interplay between financial status and mental health outcomes.

Family complexities and stress during early life: assessing biomarkers of sexual maturation in boys and girls in Germany

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Background

Early-life family complexities, such as parental separation, have been negatively associated with several short- and long-term life course outcomes, such as health, social relationships, or school performance. Most studies attribute these adverse life course outcomes to children's chronic stress exposures resulting from family complexities, while failing to empirically prove the underlying mechanism.

Objective

We aim to investigate the association between family complexities and stress during early life in boys and girls in Germany, focusing on the role of the underlying stressors of exposure timing and the social family environment.

Methodology

Exploiting unique data from the longitudinal 'German Health Interview and Examination Survey for Children and Adolescents' (KiGGS; waves 2003–06, 2009–12, and 2014–17), we utilize biomarkers of sexual maturation (i.e., age at first seminal ejaculation in boys and age at menarche in girls) to examine the association with parental separation on a sample of $n=6,243$ boys and girls in Germany (applying survival analysis).

Findings

Initial findings show overall increased probabilities of sexual maturation for children with separated parents that reverses over age. This trend seems to be driven by girls and no reverse in trend is observed for boys.

Stay-at-home: The impact of the COVID-19 lockdown on household functioning and ART adherence for people living with HIV in three sub-districts of Cape Town, South Africa.

Linda Campbell (University of Antwerp; Ghent University), Lucia Knight (University of Cape Town, University of Western Cape), Caroline Masquillier (University of Antwerp), Anton Delport (University of Western Cape), Neo Sematlane (University of Western Cape), Lorraine Tanyaradzwu Dube (University of Western Cape), Edwin Wouters (University of Antwerp, University of the Free State)

Introduction

The COVID-19 pandemic has posed unprecedented challenges to public health systems worldwide, with significant implications for the management of chronic conditions such as HIV/AIDS. In South Africa, where the burden of HIV/AIDS is high, the South African government imposed a lockdown in March 2020 to control COVID-19 transmission. Lockdown may affect people living with HIV's (PLWH) antiretroviral therapy (ART) adherence. Antiretroviral therapy (ART) adherence is crucial for health outcomes of people living with HIV (PLWH). Individuals' adherence is impacted by a complex interplay of individual, community, and household factors, with the household gaining increasing recognition as a significant factor. Amidst the global imperative to improve ART adherence, this study aims to investigate changes in the individual, social and structural factors affecting ART adherence between the pre- and post-level-five lockdown, and to examine correlates of ART adherence during the level-five (strictest) lockdown. Understanding the impact of these measures on antiretroviral therapy (ART) adherence is crucial for informing targeted interventions to support PLWH during periods of crisis.

Methodology

Baseline data for a cluster-randomized control trial were collected from 152 PLWH in Cape Town sub-districts from October 2019-March 2020 when the lockdown halted data collection. Subsequently, these participants were followed-up by telephone in June-July 2020; 83 PLWH participated in the follow-up questionnaire. Random effects models were used to analyze: (1) changes between baseline and follow-up and (2) correlates of adherence during lockdown. Analyses evaluated factors such as socio-demographic characteristics, ART adherence, household dynamics, and experiences during the COVID-19 lockdown.

Results

At follow-up, there was an increase in the odds of being below the poverty line ($2.41, z = 2.19, p = 0.03$) and the odds of experiencing violence decreased. Measures for well-being, household functioning, stigma and HIV competency improved: there was a decrease in the odds of experiencing household HIV stigma between baseline and follow-up for those feeling blamed by their household members because of their HIV status (aOR: $0.15, -2.33, p = 0.02$). There was similarly evidence of a decrease in reporting any instance of violence (emotional, physical, sexual) between baseline and follow-up (aOR: $0.08, z = -2.2, p = 0.024$). There was also evidence of a

decrease in the odds of not having a feeling of togetherness in the household (aOR: 0.29 $z = -2.10$, $p = 0.04$). Despite concerns about the impact of the lockdown on mental health, there was evidence of improved individual well-being at follow-up (OR 9.50, $p < 0.001$), particularly among those in supportive household environments.

There was no evidence of an association between adherence score and socio-demographic variables such as age, gender, education, or household income. Violence, depression, food insecurity, and stigma were associated with poorer ART adherence; participants who reported restricting adult food consumption to feed young children were more likely to have worse adherence (OR -1.19, $p = 0.02$). Similarly, experiences of intimate partner violence (IPV) were strongly associated with lower adherence scores (e.g., any reported violence: OR -2.09, $p = 0.01$). Experiencing stigma (insults, blame and gossip in the household) was negatively associated with adherence scores: those experiencing blame averaged 4.06 adherence points fewer than those who did not ($t = -2.86$, $p = 0.002$). Those reporting feeling more depressed during the lockdown also reported lower adherence scores (-1.17 , $t = -2.47$, $p = 0.02$). Participants also had lower odds of reporting depression with indicators of improved household functioning (household members don't raise voices when angry: aOR: 0.27, $z = -2.04$, $p = 0.04$)

Conclusion

This study investigated antiretroviral therapy (ART) adherence in Cape Town, South Africa during the COVID-19 lockdown. Implementing lockdowns to curb COVID-19 transmission resulted in a reorganization of social and economic life in South Africa on an exceptional scale, impacting ART adherence via multiple interconnected pathways. The results indicated that the impact of lockdown was unequal, dependent on a complex web of individual, social and structural factors. The results furthermore indicate the importance of household level factors in ART adherence during lockdown, as well as individual and structural level factors. In order to support ART adherence during lockdown, the South African government should facilitate access to food and medication, especially for households with children, as well as access to IPV support services. Qualitative research should be undertaken to clarify the pathways by which individual, social and structural factors are linked to ART adherence during lockdown. Further research should assess whether interventions that improve household functioning and household HIV competency enable PLWH to adhere to ART—even in times of crisis.

The effect of parenthood on alcohol consumption in different countries – A longitudinal analysis

Philipp Linden (Fulda University of Applied Sciences), Nadine Reibling (Fulda University of Applied Sciences)

Background

The transition to parenthood and family roles are important factors influencing health and life expectancy. Health-related behaviors thus represent an important mechanism through which the relationship between parenthood and health is mediated. Parenthood often leads to a change in values and orientations promoting healthy behaviors. However, taking the role of a parent is also associated with demands that generate stress and significantly limit both time and energy resources.

Objective

This study investigates how the birth of the first child influences harmful health-related behavior like drinking alcohol. Previous studies in this area mostly examined cross-sectional data and yielded inconsistent results. With these data, it is also difficult to distinguish between the effects of parental education and selection effects that influence both parental health and health behaviors.

Methods

We harmonize household survey data from different countries – Australia, the United States and Russia – over the years of 1999 to 2019. Our estimand is the (time-dependent) effect of parenthood on the self-reported measure if respondents drink alcohol on a regular basis for men and woman that become parents. This is often referred to as the average treatment effect on the treated (ATT) and can be defined as difference in the probability (P) of alcohol consumption ($Y=1$) if parents ($X=1$), instead of having their first child, had remained

childless ($X=0$). The first term of this difference, the respective probability under the condition of parenthood, can be observed as (time-specific) proportion of parents who engage in drinking adjusted for control variables Z . However, because we cannot observe parents under the condition of being childless this probability is counterfactual so that we are unable to measure it directly.

Therefore, the challenge in each analysis of the effect of parenthood (or any other ‘treatment’) is to find reasonable approximations of this counterfactual. This can be done by combining available data (on parents and childless persons) with theoretical assumptions on how comparable these data are with the counterfactual of interest. In this analysis, we make three different assumptions, each of which corresponds with a specific analytical approach: First, we assume that parents and childless persons are similar on measured covariates Z by specifying a simple pooled OLS regression model (POLS). A second assumptions states that parents would have followed the same trajectory as childless persons over time, if they had not become parents leading to a pooled OLS general fixed effects model (POLS-GFE). Finally, we assume that parents would follow their pre-birth trajectory if they had not become parents. The corresponding regression model is specified as pooled OLS general trends model (POLS-GT). With an observation window of 20 years, information on regularly alcohol consumption and relevant sociodemographic factors, this longitudinal data structures as well as our three-step analysis strategy has two decisive advantages over previous approaches: It allows us to determine the average treatment effect of parenting on alcohol consumption and to track the impact of the time course on health-damaging behavior.

Results

The proportion of drinkers is high in all three countries surveyed: eight to nine out of ten people state that they drink regularly. In addition, proportions are slightly higher for men than for woman. With the onset of parenthood, the proportion of drinking mothers drops significantly, while the proportion of drinking fathers shows hardly any change. Thereby, Australian, and Russian mothers decrease their alcohol consumption before or during pregnancy, while the proportion among US-American mothers declines only after birth. In addition, the declines in drinking are not sustainable, as we also see an increase in the respective proportions over time after birth.

Conclusion

Healthcare professionals and policy makers should ensure that support and education programs also have a long-term effect to consolidate the positive influence of parenthood over time. Mothers in particular need more support in not (re)adopting harmful behavior after a certain period of abstinence. Fathers can contribute to this by making them aware of the consequences for their own health and their function as a role model for their children.

Health Disparities: Exploring the Reciprocal Relationship between Health and Social Inequality, Thematic Session – Chair: Malgorzata Mikucka – Room K.201

Exploring sociodeterminants of health in the aging immigrant community: A narrative review

Ana Carolina Texeira Santos (University of Luxembourg), Leandro Gomes (State University of Amazonas PPGICH/UEA; Federal University of Amazonas), Anja Leist (University of Luxembourg)

Introduction

Global migration, characterized by a continuous rise in migratory flows worldwide, involves approximately 281 million individuals, constituting around 3.6 percent of the global population. This phenomenon has the potential to influence susceptibility to adverse emotional and health outcomes, especially impacting vulnerable demographics such as older adults and individuals with limited socioeconomic resources. These challenges are commonly encountered by many immigrants, with their experiences shaped by various socioeconomic factors, including education, income, geographic region, social support, healthcare access, and occupation. Recognizing

these dynamics is crucial to promoting health equity and identifying individuals facing heightened health risks. When discussing equity, it is imperative to address the need for understanding living conditions and health, establishing technical, social, and political mechanisms to tackle potentially adverse conditions faced by individuals.

In Luxembourg, a country marked by a myriad of migratory flows, migration's implications are particularly important. According to the 2021 census, nearly half of the population (49.3%) comprises individuals born outside the country and 47.2% of the population consists of non-Luxembourgish individuals. Considering those with an indirect migratory background, having at least one parent born abroad, this percentage increases to 73.7%. The immigrant influx in Luxembourg started in the late 1960s and early 1970s, with the Portuguese community emerging as the largest immigrant group. This was predominantly driven by economic imperatives, responding to the heightened demand for a workforce during that period.

The IMILUX, a 2-years project launched by the University of Luxembourg in 2024, was conceived to comprehensively exploring the socioeconomic, cultural, and health variables related to immigration and aging in Luxembourg, with a specific focus on identifying the socioeconomic determinants of health within this population. In this presentation, we will provide an overview of the ongoing bibliographic review within the IMILUX Project.

Methodology

A narrative literature review is currently underway, involving an extensive bibliographic exploration across various databases, including EMBASE, PsychINFO, Scopus, PubMed, Science Direct, Web of Science, Scielo, PsycINFO, and Sociological Abstracts. The search extends to gray literature on platforms like medRxiv and the ProQuest Dissertations & Theses Global. The search strategy involves combining terms related immigration and sociodeterminants of health, with a dedicated focus on aging. Furthermore, the study will incorporate Bourdieu's theory of capitals, encompassing key concepts like *habitus*. Defined as the ingrained dispositions and behaviors shaped by one's social environment, *habitus* will play a crucial role in understanding the experiences of older immigrants. Additionally, economic, social, and cultural capital will be employed to comprehend access to healthcare and lifestyle.

Results

As the research progresses, the projected outcomes are expected to provide valuable insights into crucial aspects of the health and well-being of older immigrants. Immigrants, compared to non-immigrant populations, frequently encounter less favorable health outcomes. Preliminary findings will entail a deeper comprehension of these disparities, considering sociodeterminants and accounting for characteristics such as income, education, chronic diseases, lifestyle, time of arrival in the host country, and nationality. Examining variations between first and second generation immigrants is essential for comprehending the complexities of migration and its influence on societal structures spanning different generations. Additionally, the review will investigate the influence of a sense of belonging and the concept of acculturation on the mental health and well-being of immigrants.

Conclusion

The IMILUX aims to enhance our comprehension of health dynamics among older immigrants in Luxembourg, emphasizing both cognitive and physical aspects. This presentation will highlight the literature review conducted as part of the project, intending to offer valuable insights into the intricate interplay of socioeconomic, cultural, and health factors affecting older immigrants. Acknowledging the ongoing research, the anticipated outcomes are poised to make significant contributions to the field of migrant health, offering insights into the existing literature. This endeavor holds the potential to offer perspectives on various immigrant groups and strategies to enhance the health, well-being, and social integration of this community.

Recognizing these barriers is imperative for developing interventions and informing more inclusive policies that advance health equity for both older immigrants and their descendants. The relevance of research projects, such

as IMILUX, is highlighted, emphasizing their importance for monitoring and understanding immigrant flows and conditions, thereby assisting in the development of effective actions and policies.

For future work, it is suggested to develop a comprehensive exploration of existing policies for immigrants. This could involve detailing the mechanisms and institutions in place for the inclusion and monitoring of immigrants. In the context of IMILUX, a crucial aspect would be to identify points of convergence for these immigrant groups within the physical and virtual territories of Luxembourg. Understanding the existing support structures and communal intersections will contribute to a more holistic approach in shaping inclusive and effective policies for the well-being and health of older immigrants.

When did health inequalities emerge?

Eero Lahelma (University of Helsinki)

Introduction

Health inequalities are a scourge that has been extensively studied over the last few decades, and persist across countries, age groups, genders as well as most illnesses and causes of death. However, little is known about their historical origins. The main research question of this review is: When did health inequalities emerge?

Methodology

The examination is based on literature review covering the history of health inequalities from the prehistorical origins through Middle Ages to the modern era.

Results

Five phases are distinguished to highlight important events in the evolution of health inequalities. Firstly, in the prehistorical era, life expectancy remained low, i.e., only 20-40 years. The early human communities were small, and their limited resources were distributed according to need. These communities were, presumably, relatively equal, including likely even health. Secondly, the invention of agriculture about 10000 years ago led to societies, which produced surplus and distributed it no longer according to need, but power. Over time, this gave rise to the emergence of social inequalities as there was a deep cleavage in power and resources between the small peerage and the large majority of common people. Whether these social inequalities boosted health inequalities as well, is poorly known. Major health problems included maternal and child mortality, as well as epidemics of infectious diseases, such as smallpox, cholera, typhus and plague, which reached whole populations in the lack of effective medical treatments. Thirdly, towards late Middle Ages, social inequalities were institutionalized between the estates, including also intermediate classes. Epidemics of infectious diseases raged “democratically” throughout population subgroups. Small scale studies were initiated, and life expectancy was found basically as low as earlier. Graded inequalities in mortality were confirmed for the population of the 17th century Geneva, but overall, the findings of studies were heterogeneous. Fourthly, coming to the modern era, the breakthrough of industrial capitalism in the 18th and 19th century brought about major social structural changes in societies. The population was divided into hierarchical social classes, including the new working class, which was exposed to the unhealthy working conditions in the factories and poor living conditions in the crowded neighborhoods. Studies focusing on industrialized societies, such as Britain, Germany and France, reported modern type of hierarchical class inequalities as well as related health inequalities. Fifthly, coming to the 20th century, novel research methodologies and data sources improved the research on health inequalities. There was no question whether health inequalities existed, but their causes remained less well known and debated. Finally, the British the Black Report on Inequalities in Health (1980) changed the terrain: health inequalities became widely recognized, and studies increased first gradually and soon exponentially.

Conclusion

It is unlikely that health inequalities have been there throughout the human history. However, strong conclusions are not warranted since evidence on prehistoric societies is limited and indirect. While early signs were seen in

late Middle Ages, the breakthrough of industrial capitalism was the true start of modern hierarchical class inequalities in health, as exemplified by several European countries. Currently, health inequalities cover all societies, from poor ones to the most affluent welfare states, the latter being named “the Nordic paradox”. The idea of tackling health inequalities was raised already in the 17th century Britain by William Petty. However, the task has turned a tough one, with minor results despite extensive programs in many countries. Policies tackling health inequalities needs to be prioritized much more than has been done so far.

Income inequality and self-rated health: A global perspective through harmonized cross-sectional data.

Malgorzata (Gosia) Mikucka (Mannheim University), Oliver Arránz Becker (Martin-Luther-University Halle-Wittenberg), Christof Wolf (GESIS - Leibniz-Institute for the Social Sciences)

Introduction

The literature proposed diverse theoretical links between inequality and health. The rarely questioned absolute and relative income effects, combined with the decreasing marginal utility of income, are themselves enough to suggest that income redistribution could improve population health (Deaton, 2003). However, much of sociological reasoning goes further, proposing that humans are evolutionarily predisposed toward fairness, and unequal environments may adversely affect their health through psychosomatic processes (Pickett & Wilkinson, 2015; Wilkinson & Pickett, 2006, 2017).

Despite theoretical developments, the literature remains divided on whether income inequality directly impacts individuals' health. Various literature reviews present conflicting views, with some asserting that accumulated evidence supports the negative health consequences of income inequality (Patel et al., 2018; Pickett & Wilkinson, 2015; Tibber, Walji, Kirkbride, & Huddy, 2022; Wilkinson & Pickett, 2006), while others deem these claims empirically ungrounded (Deaton, 2003; Monheit, 2022). Some studies find middle-ground positions, demonstrating statistically significant but substantively small effects (Kondo et al., 2009; Truesdale & Jencks, 2016). This paper aims to contribute to the debate by re-evaluating the link between changing income inequality and individual health, addressing some methodological shortcomings of prior research.

Methodology

This analysis uses cross-sectional data from the Social Data Recycling (SDR) research program, which harmonized post-hoc survey data from 23 international survey projects, covering 4.4 million respondents across 3,329 national surveys (years 1966–2017), and providing comparative data for 156 countries. The SDR database v.2.0 includes the harmonized (“target”) variables together with methodological indicators describing the source survey and questions (Slomczynski & Tomescu-Dubrow, 2018; Tomescu-Dubrow et al., 2024). The unprecedented number and diversity of countries makes the SDR a unique data source, perfectly suited for studying the relationship between income inequality and individual health.

We measure individual health with the harmonized self-rated health measure. The decision to use an individual measure contradicts the research tradition of relying on macro-level indicators, such as life expectancy and infant mortality. However, this decision is guided by recognition that individual-level measures are better suited to capture individual-level mechanisms than macro-level outcomes.

To model the relationship between inequality and individual health, we use multilevel regression. We define models where individuals are nested within country-years and within countries. We use a framework of cross-sectional time series analysis: we model separately the cross-country differences in income inequality (this variance is captured by country-specific averages) and changes in inequality occurring within countries (this variance is captured by deviations from the country-specific average). Thus our estimates of the relationship between inequality and health do not reflect the time-invariant, unobserved between-country heterogeneity which is typically substantial and may reflect cultural, institutional, and other differences.

Aiming for a parsimonious model, we only include essential controls: gender and age (including the interactions and non-linear effects) at the individual level, and GDP per capita and its changes at the macro level.

Results

Our first estimates indicate that an increase in income inequality corresponds to a worsening in individual health. This effect is significant at 95% confidence level but in substantive terms it is small. Specifically, a 10-point (on a 0-100 scale) increase in Gini within a country corresponds to reduction in average health by 0.065 point, i.e. 1.6% of the total range of our health scale.

Conclusion

Our first results indicate that growing income inequality correlates with worsening of individual health, however the effects are substantively small. This pattern does not show unequivocally across various survey programs, demonstrating the importance of using a broad range of data and replication studies.

Are care networks (re)producing inequalities? An intersectional exploration.

Rieke van Dijk-Hengelaar (Amsterdam University of Applied Sciences), Margo van Hartingsveldt (Amsterdam University of Applied Sciences), Tineke Abma (Leyden Academy), [Petra Verdonk](#) (Amsterdam UMC)

Background

Becoming an informal carer for someone with an acquired brain injury (ABI) causes a dramatic disruption of daily life. Caring takes place in complex care networks in which carers often do not feel involved. When focusing on carers with a migration background, it becomes clear that collaboration with professionals often (re)produces inequality, as implicit bias amongst professionals influences the collaboration process and often downplays carer knowledge.

Objective

This study sought to understand how carer experiences were shaped by aspects of diversity to enable an in-depth understanding of power structures in care networks.

Methods

An intersectionality informed qualitative study design incorporated three informal group conversations (N=32), semi-structured interviews (N=21) and three dialogue sessions (N=7) with carers caring for someone with an ABI. A critical friend and a Community of Practice, with carers, professionals and care recipients (N=8) contributed to the analysis.

Results

Three interrelated themes were identified as different layers of the carer experience: (a) *I need to keep going*, showing carers' personal experiences and how experiences are related to carers social positioning; (b) *The struggle of caring together*, showing how relatives and social environment supported the carer but added expectations; and (c) *Trust is a balancing act*, showing how trusting professional support proves challenging for carers and how this trust is influenced by contextual factors at the organizational and policy levels.

Conclusion

We conclude that there is a need for diversity-responsive policies within care organizations that focus on actions to diminish assumption-driven care and to create a space where carers who are not the societal norm can feel heard.

Reconsidering Digital Ageing: Boundaries, Transformations and Meanings, Thematic Session – Chair: Francesco Miele – Room K.202

Addressing innovations in digital ageing in Italy

Fabiola Balestrieri (University of Bologna)

Abstract

European countries are witnessing a significant population ageing process due to increasing life expectancy and decreasing birth rates (Pugliese, 2011). The progressive ageing of the population, the diversification of the needs of the elderly and the decreasing number of caregivers available to meet them, increase the demand for innovative technologies applied to long-term care services. In an increasingly technologically advanced and constantly hyper-connected society, new technologies are at the service of patients, totally reconfiguring both the experience of illness and its management: the constant and immediate transmission of information between patient and physician (Peinado et al., 2009), the creation of peer support networks (Cornejo et al., 2013) and facilitated communication between caregivers and relatives (Mort et al., 2013), not only make us understand how telecare technologies are conceived as tools and means of support for patients and their care networks, but also how today an intricate network of actors is being articulated who have the most onerous task of making everyday and home care as concrete and efficient as possible. On the other hand, there are numerous points to watch out for when applying forms of digital innovation to the context of health, and in this case the health of frail elderly people: techno-disparities (Moretti, 2020), grey digital divide (Unece, 2021), digital health literacy (Nymberg et al., 2019; Arcury et al., 2020), privacy renegotiation (Berridge, 2016).

The research presented here is a part of the doctoral project focusing on the needs of elderly people, caregiver and healthcare professionals using the services offered by the Società Dolce Social Cooperative - where the internship took place - and how a digital app can help fill unmet care needs.

The defined methodology involves the desk study on the literature and the application of co-design as a creative method. The co-design approach values the experience of the end-users of a technology (end-users) - in this case elderly people and caregivers - and therefore actively involves them in the mHealth system design process (Burke et al., 2015; Eyles et al., 2016) together with other stakeholders. The stages designed by Sanders and Stappers (2008; 2014) are the most widely recognized and used in the co-design literature. Here, the pre-design phase will be discussed, which aims to understand the activities that caregivers routinely perform in the management of the older person's illness, unmet needs in the context in which they live, and the use of digital technologies. This was done by: finding and studying the Service Charter for a general overview of the services for the elderly offered by Società Dolce; visiting a day care center and a nursing home for the elderly where informal interviews with the facility managers and operators took place; 19 semi-structured interviews were conducted with social and socio-medical operators dealing with services for the elderly offered by Società Dolce. The recruitment of the operators took place through the snowball sampling technique (Cardano, 2003).

The collected information will be useful for the construction of a digital platform that can be implemented in healthcare facilities and at home for the management and self-management of elderly people with different degrees of autonomy, improving their quality of life and social dimension.

Embedding robotics in home care: frontline practices of professional workers and users.

Ivan Galligani (Sant'Anna School of Advanced Studies), David Natali (Sant'Anna School of Advanced Studies)

The growing pressure of home care needs, coupled with the relative shortage of formal and informal healthcare workforce (WHO, 2016), stimulates interest in technological solutions to complement human care activities. In

this scenario, within the broader field of welfare technologies, *assistive robots* are increasingly seen as valuable options (Papadopoulos *et al.*, 2023).

Despite this hype, the actual diffusion of homecare robots in the ordinary practices of welfare services is still very limited (Ostlund *et al.*, 2023). Indeed, it is widely recognized that a greater diffusion of robotics depends not only on the strengthening of the *technological readiness* of robots but even more on the level of *social acceptance* and *organizational preparedness* in the field (Pekkarinen *et al.*, 2020). The enactment of ‘robotic home care’ requires not only technological innovations but also *socio-technical ones* (Cresswell *et al.*, 2018). The concrete practice of care, particularly home care, rather than being simply *determined* by technology, is the result of a complex interaction between techno-material, spatial, organizational, cultural, relational, and agentic factors. The articulation of these elements constitutes the *infrastructures* that enable the actual functioning of care (Danholt & Langstrup, 2012). It means that, if there is a willingness to move away from pilot settings, robotic applications must be embedded into existing care practices and routines and, through a creative practice of innovation, build a new functioning care infrastructure.

Nevertheless, to date, the receiving social environment is not so welcoming to such innovations. While clinicians and managers often consider robots as valuable solutions for promoting care effectiveness and efficiency, professional and informal caregivers tend to be more skeptical (Tuisku *et al.*, 2023). Especially for care professionals, even setting aside the unjustified (albeit widespread) fear of being substituted by robots, care workers are worried about the risk of *mechanization* of care (Frennert *et al.*, 2021). These threats are represented as a “cold” operationalization of therapeutic practices, and a subordination of professional practices under the technological necessities, reconfiguring workers like “machine babysitters” (White, 2019), thus determining a substantial loss of professional autonomy (Sharkey & Sharkey, 2012; Hamblin, 2022). Moreover, informal caregivers too fear the loss of ‘human touch’ and, paradoxically, the reduction of autonomy due to the inability to manage robots (Frennert *et al.*, 2021).

To sum up, from the viewpoint of robotics advocates, it is only a matter of strengthening operators’ and beneficiaries’ trust in robots and adopting the most effective organizational arrangements to meet users’ needs (Tuisku *et al.*, 2023). Whereas, from the frontline users’ point of view, what is at stake is often rather the *domestication* (Gibson & Brittain, 2023) and *appropriation* (Miele, 2023) of the new tools in order to rearrange them in a useful way with existing practices and to create new ones (valuable from their point of view).

In this perspective, the authors present first findings from broader research on the political, social and organizational prerequisites for the adoption of robotics in home care, conducted as part of an Italian NRRP-funded project: FIT4MEDROB. The findings are based on a series of focus groups and interviews involving clinicians, professionals and patient representatives, as well as field observation of relevant cases of robot experimentation for home care in the context of FIT4MEDROB.

The analysis will focus on the perspectives, critical concerns and adopted solutions by frontline professional and informal stakeholders during the process of embedding new tools in existing (as well as newly generated) care practices.

Enacting algorithmic technologies in the co-design of eHealth interventions

Riccardo Pronzato (University of Bologna)

Abstract

This contribution the co-design of technologies directed at older people as an opportunity to investigate how algorithmic technologies are enacted by different cultural practices and interpretations and how diverse forms of social power are brought into being within the process. Drawing on Seaver’s conceptualization of algorithms “as culture” (2017) and, focusing on the co-design of an e-learning platform for informal caregivers of patients

with dementia (project AGE-IT, PNRR PE8 “Age-It”), I bridge perspectives from health sociology and critical algorithm studies, in order to better understand the intersection of technological change, health, and social power.

Recently, there has been a notable shift in the approach to creating new technological artifacts for health interventions directed at senior citizens and patients in general. Following a first transition from supplier-centered design to user-centered design, the co-design approach – where designers, service providers, and users collaborate to identify needs, issues, and challenges – has emerged as a fruitful strategy to produce technologies that can empower participants and address their needs (Ward et al., 2018; Dietrich et al., 2021). Co-design requires involvement and active participation among different stakeholders, such as healthcare professionals, end-users (e.g., patients, families, and caregivers), managers, and IT experts, to favor improvements, for example, in the conditions of patients and their caregivers.

Within this framework, eHealth interventions are often provided through digital platforms, which have become infrastructural elements in human sensemaking processes and in the automation of societal dynamics (van Dijck et al., 2018). While computational systems operate in ways that can seem neutral and helpful, there is consensus among scholars that these technologies are not neutral intermediaries, as there are specific socio-cultural norms, business goals and political relations embedded in their design and functioning (Schwennesen, 2019; Pronzato, 2023; Torenholt and Langstrup, 2023). This is not surprising as power asymmetries are part of the history of all human technologies, their production, diffusion and adoption.

To better understand algorithmic systems, following a STS sensibility and a practical approach to culture (Mol, 1999; 2002), Seaver (2017) claims that these technologies can be considered “as culture”, i.e., artifacts which are “culturally enacted by the practices people use to engage with them” (p. 5). In this view, algorithms are constantly brought into being at the material level by the human activities underlying the design of digital platforms and by the ways in which individuals interpret and relate to algorithms in different settings.

If diverse human practices contribute to the enactment of algorithms, also digital platforms and the underlying datafication processes - contribute to “enact different populations as objects of concern and intervention” (Ruppert, 2011, p. 219). Indeed, the identities of the people using these technologies, such as patients, caregivers, etc. are shaped and co-constructed within networks where both human and non-human elements micro-relate in diverse ways (Lupton, 2017). Within this framework, the practices of the people co-designing, programming and using digital platforms, enact technologies in different socio-material realities and, in turn, technological functioning contributes to enact different forms of selfhood/algorithmic identities.

Given this scenario, the process of co-design emerges not only as an approach to address the “needs” of different stakeholders, but as a process deeply intertwined with the politics embedded into technological artifacts. While co-designed digital technologies can promote the agency capabilities of older patients and their caregivers, the diverse social identities and conditions of these users intertwine with the social agency of technology and can result in the automation of unintended process and inequalities. This resonates with recent studies in the co-design research area that argued that it is crucial “to re-politicize co-design” and delve into “the micro-politics of the relations that are built” into it (Huybrechts et al., 2020, p. 3). Indeed, co-designing technologies is an inherently political activity.

By bridging health sociology with perspectives from critical algorithm studies, and focusing on the co-design of an e-learning platform for informal caregivers of patients with dementia, this contribution argues for the merits of investigating how co-designed algorithmic technologies are enacted by the practices and interpretations of different stakeholders, e.g., IT designers, public institutions, caregivers, doctors, etc. Specifically, it considers co-design as an opportunity to see how technologies are enacted by different practices and perspectives and a potentially fruitful site where to explore how forms of social discrimination potentially arise from algorithmic production (Eubanks, 2019). In this scenario, findings can also provide meaningful insights into on how AI systems

directed at older people, involving the perspectives of workers, caregivers and patients, can be produced (Donia and Shaw, 2021).

“It’s difficult, but it keeps you awake and active”: Opportunities and challenges of exergames for elderly health and wellbeing

Valeria Quaglia (University of Macerata), Alessia Bertolazzi (University of Macerata)

Introduction

In recent decades, there has been a significant increase in the proportion of elderly people. According to the United Nations (2022), the percentage of people aged 65 and above is projected to rise from 10% in 2022 to 16% in 2050. This demographic shift has led to a corresponding increase in long-term diseases, including diabetes, chronic respiratory diseases, neurological disorders, and cardiovascular disease. The ageing population has put a strain on healthcare systems' capacity to plan and deliver efficient healthcare services for older individuals. Digital health technologies have enhanced the elderly's access to healthcare services, enabling them to live independently for longer and maintain their health. In addition, specific terms are used to describe digital health technologies for older adults. For example, the term 'gerontechnology' has been coined to describe the technologies designed to enhance the independence of older adults, enable ageing in place, and accommodate age-related declines and impairments (Bouma 1998). Numerous technologies and programs have been developed with the goal of supporting and enhancing the physical and cognitive functions of older adults. This presentation is based on a research study from Italy that explores the effects of exergames on the health and wellbeing of the elderly. Exergames are interactive games that use displays, specialized software, and sensors to enable physical exercise and enhance cognitive function. In these types of games, users engage in physical exercises to control and interact with the game interface. A series of persuasive strategies are used by developers (such as displaying current and past scores) to encourage the elderly being active and improve their performances. These features have the potential to motivate the elderly, although the literature highlights also a series of criticalities.

Methodology

The study aims, on the one hand, to assess the effectiveness of exergames in various settings, including nursing homes, senior groups organized by a social cooperative, and independently living elderly. On the other hand, this study aims also to critically examine the relationship between the elderly, technology, digital games and health. The methodology involved conducting in-depth interviews with all elderly (n.15) and all educators (n.3) participating in the project; furthermore, participant observation was conducted in all the locations of the experimentation in order to study actively playing elderly and their interactions. Additionally, documents produced by the educators were analyzed.

Results

The preliminary findings indicate that exergames seem to have limited physical health benefits. However, the presentation will discuss their significant role in reducing social isolation, promoting socialization among peers, and improving mental health among the elderly.

Conclusion

This study provides valuable insights into the potential of exergames in enhancing health and wellbeing of the elderly population. Despite the preliminary findings suggesting limited physical health benefits, the importance of exergames extends beyond mere physical exercise and entertainment. These interactive games play a significant role in reducing social isolation, fostering socialization among peers, social connectedness and notably improving mental health. The research underscores the need to view digital health technologies not just as tools for physical health maintenance, but also as platforms for psychological and social wellbeing, especially in the context of an aging global population.

Studying (Non-)Participation in Health Research: Experiences, Research and Theories,

Thematic Session – Chair: Carla Ferreira Rodrigues – Room K.203

Not another survey! Non-participation in web-based respondent driven sampling among Belgian men who have sex with men

Estelle Thunissen (University of Antwerp), Veerle Buffel (Free University of Brussels), Linda Campbell (University of Antwerp), Edwin Wouters (University of Antwerp)

Introduction

Respondent driven sampling (RDS) has been developed to overcome sampling challenges in vital health research among hidden populations, and to provide a basis for population inference (Lu et al., 2012) (Abdul-Quader, Baughman, & Hladik, 2014) (Mauck et al., 2019). The method uses chain referrals with structured incentives as a recruitment strategy. RDS is sensitive to relatively small percentages of non-participation compared to other sampling methods, as long unbroken recruitment chains are necessary for RDS population inference.

The majority of successful RDS studies are set in low-or middle-income countries where, in contexts of poverty, and suffering further economic and social disadvantage, participants may be more motivated to participate in research, especially when studies offer incentives (Singer & Ye, 2013). RDS that rely on incentives to guarantee participation may not therefore be suitable for MSM populations in a high-income settings with relatively lower levels of stigma: incentives have relatively less value, and motivation may be low due to existing right protection and sexual health access. In their systematic review on RDS reporting White et al (2015) found little to no value for using RDS in European countries.

In the early 2010's, Web-based RDS (WEB RDS), where respondents recruit each other online, was heralded as a promising new strategy of sampling invisible populations such as MSM in high income settings (Wejnert & Heckathorn, 2008). However, after a decade of research, it remains unclear if WEB RDS is suitable for sampling of MSM in high-income countries (Strömdahl, Lu, Bengtsson, Liljeros, & Thorson, 2015). In this article, we therefore evaluate two WEB RDS among MSM in Belgium, focusing on (non)participation and (non)recruitment.

Methodology

This study presents the results of a process evaluation of two Web RDS, one without incentives and one with incentives. We followed both the brief and extensive MRC guidelines for process evaluation developed by Moore et al (2015). Quantitative findings were summarized using a narrative approach (Elliott, 2005). Research documents were analyzed and codes generated using a thematic inductive approach, where themes that recurred throughout the data were categorized into broader descriptive categories. (Elliott-Mainwaring, 2021). Findings from the quantitative analysis were integrated at this phase and a coherent line of argument was subsequently generated.

Results

The final samples (RDS-I n=32 , RDS-II n=127) did not reach the target sample size of 625, so we cannot compensate for RDS design effect. The number of waves were 2 for RDS I and 7 for RDS II, both too short for population inference. RDS-II (with incentives) significantly outperformed RDS-I (without incentives). Even so, sampling in RDS-II died out predominantly through non-response; almost two-thirds of the invitations sent by participants did not receive a response. Non-recruitment was a further issue, with just under a third of respondents not inviting others to the survey.

During focus groups on participation barriers, community organization representatives stated MSM belonging to their organization suffer from severe survey fatigue due to the overwhelming number of survey invitations received. They also reported their members were unhappy about the sheer number of studies conducted

regarding their sexual behavior, versus other aspects of their lives. The survey topic was also considered a barrier to recruitment: during the non-response analysis MSM stated that they had not invited others because of the sensitive nature of the questions.

Conclusion

High degree of non-participation and non-recruitment despite a theoretically optimal incentive structure and amount indicate limitations to WEB RDS viability among MSM in Belgium. The high survey fatigue and non-participation among MSM seen in our study deserve further investigation. This survey fatigue may be in line with a wider societal trend of online survey oversaturation and declining response rates, or it may be an artefact of MSM being designated an at-risk population and being disproportionately targeted by surveys. The phenomenon of 'over-research', when particular populations and communities attract disproportionate research attention, is under-researched, and there is significant research gap regarding over-research among at risk populations targeted by health research (Sukarieh & Tannock, 2013). The mechanism inducing non-participation among MSM could be similar to spatial bias, where some areas are more prone to being researched because of the particular features of their populations, and thereby create resistance to research occurring at all (Neal, Mohan, Cochrane, & Bennett, 2016). The sexual health topic-specific research fatigue we found among Belgian MSM is an additional concern that should be addressed in future studies. The sense that researchers are driven by different agenda's to the people they are researching can produce frustration with high levels of research attention (Beebejaun, Durose, Rees, Richardson, & Richardson, 2014) (Clark, 2008).

Designing a qualitative study exploring experiences of menopause and multiple sclerosis: Benefits of co-design

Imogen Collier (Queen Mary University of London), Ruth Dobson (Queen Mary University of London), Samantha Quaife (Queen Mary University of London), Daisy McInnerney (Queen Mary University of London)

Introduction

More women than men live with multiple sclerosis (MS). The majority are diagnosed during their reproductive years and hence go through the menopausal transition while living with the disease. Challenges relating to ambiguous clinical presentations are well described in both menopause and MS, and this is further complicated by various symptoms prevalent in both conditions that can overlap, such as fatigue, memory and cognition problems, and difficulty with bladder and sexual function. Prior research has established that hormonal changes can impact MS (for example, during pregnancy), however the impact and experience of menopause for people with MS remains under-researched and poorly understood. Existing studies have investigated the potential impact of menopause in very narrow terms, focusing on possible outcomes such as disability progression and increased symptom severity, while neglecting to consider possible psychosocial impact.

As part of a program of work around MS and menopause, we worked with a patient and public involvement (PPI) group to design a qualitative study aiming to fill this knowledge gap. Co-design in health research can help to ensure that a study is acceptable, feasible and accessible to participants. It can also help to ensure that research questions, priorities and aims are relevant to patients, and that outcomes are applicable and will be of benefit for the intended population.

Aim

To work with a PPI group to design a qualitative study exploring experiences of menopause and multiple sclerosis.

Methodology

PPI members were people with MS living in the UK who had experience of menopause and were recruited via existing PPI networks and via social media. Initial focus groups aimed to identify and prioritize questions for the study to address, as well as to discuss the acceptability and feasibility of conducting a qualitative study with

participants with MS. The researchers subsequently produced an interview topic guide based on subjects that PPI members had cited as important. We sent the guide to PPI members for review and made alterations on receipt of their feedback. We then developed the study protocol and applied for the necessary ethical approvals. The second round of focus groups provided an opportunity to update PPI members on the impact that they had had on the final study design. PPI members were provided with anonymous digital feedback forms after each focus group, on which they could raise additional points or disclose any personal experiences that they did not feel comfortable expressing in the group environment.

Results

Impact on the study design Aspects of the study design that resulted from or were confirmed as important by the co-design process include: the exclusion of premenopausal women; UK-wide recruitment (avoiding a London-centric sample); inclusion of participants from groups who have historically been excluded and underrepresented in MS and menopause research; offering a choice between in-person and virtual data collection, and between taking part in a 1:1 interview and in a focus group; providing participants with compensation and travel expenses; informing participants of the study outcomes and impact.

Benefit to the PPI members Feedback from PPI groups was positive, with members indicating that they understood the reason for and importance of the study, felt able to ask questions, and enjoyed participating in the event. The majority of PPI members remain involved with the project to date and have taken part in further design activities, including cognitive interview-type work to develop a questionnaire for a quantitative study.

Benefit to the researcher This work was primarily carried out by a PhD student who was new to the field of MS and menopause. Working closely with people with MS from the beginning of the project allowed her to begin to understand the experiences and major concerns that many people with MS have. The focus groups also helped to inform the evolution of the theoretical underpinnings of her research; she noticed two distinct ways that PPI members talked about menopause (as a medicalized experience necessitating treatment versus as a natural, universal phase of life). This led to exploration of social constructionist theories of health and gender which have become key themes of her PhD.

Conclusions

Our co-design activities helped us to develop acceptable and feasible recruitment and data collection procedures, as well as to ensure that the research priorities were relevant to people with MS. Creating opportunities for people with MS and menopause to meaningfully engage with and contribute to the design of research from the very beginning of the project has allowed us to build enduring relationships with patient stakeholders who see the value in the research project and are keen to support it in the longer term. Planned future co-design activities include pilot testing a questionnaire for a quantitative study and holding focus groups to explore possible creative approaches to research dissemination and impact.

Perceptions, barriers and facilitating strategies of inclusive research: a qualitative study with expert interviews

Latifa Abidi (Maastricht University), Julia van Koeveringe (Maastricht University), Mareike Smolka (Wageningen University & Research), Brigitte van Lierop (Frans Nijhuis Foundation), Hans Bosma (Maastricht University), Jessica Allewa (Maastricht University), Nikita Poole (Maastricht University), Gera Nagelhout (Maastricht University)

Introduction

Although the concept of inclusive research has been applied particularly in the field of learning disabilities, attention to inclusive research is growing in various fields of research. Inclusive research is increasingly recognized as an essential component of ethical and high-quality research. Studies indicate that, besides living with a disability, being female, being genderqueer, being poor, having little formal education and/or belonging

to certain ethnic groups can mean that people are less involved and underrepresented in scientific research. While some practical challenges to inclusive research have been identified, it usually requires extra budget and time, little is known about the barriers experienced by researchers. We also have a limited understanding of how inclusive research is conducted in health sciences, social sciences, and (bio)medical sciences. In studying how researchers from these fields experience and view inclusive research, we aim to support the development of inclusive research methods and help address potential challenges in applying such methods. This study explores (1) what inclusive research is, (2) why inclusive research is important, (3) which barriers are experienced during the research cycle, (4) which strategies researchers propose and deploy to address these barriers.

Methodology

A purposive sampling approach was employed to recruit participants who could provide rich and relevant insights within the available constraints. We conducted one-on-one, semi-structured qualitative interviews with 15 researchers. All interviewees were approached via email for recruitment. We included (1) researchers who have experience with carrying out inclusive research in their field, and (2) researchers who study inclusive research as a topic and also have experience with carrying out inclusive research. Interviews were recorded and transcribed. Qualitative content analysis was conducted to identify and categorize codes and themes. Code development was based on deductive and inductive reasoning, starting with deductive coding but remaining open to new topics suggested by the data.

Results

We identified three important aspects of inclusive research: involvement of researched groups, research accessibility, diversity and representativeness. Societal, methodological, educational and ethical arguments were provided as reasons as to why inclusive research is important. Main barriers were researchers' lack of skills, lack of time, non-inclusive research materials, a closed attitude of the researcher and a lack of budget/funding. The following strategies to facilitate inclusive research were mentioned by the interviewees: improving the skills of researchers, awareness of and sensitivity to inclusiveness, creative, suitable and comfortable measurement settings and instruments for participants, providing resources, structural changes, having co-researchers think along about the design and execution of the study, using toolboxes.

Conclusion

This study has identified important facilitators and barriers for more inclusive research practices at various stages of the research process, applicable to a wide range of academic fields such as health sciences, psychology, medicine and biomedical sciences. Societal, methodological, educational and ethical arguments were provided as reasons as to why inclusive research is important. There is not one correct way to conduct inclusive research. Rather, an inclusive mindset is needed among researchers and an expansive, continuously developing vision of inclusive research is necessary for its increased implementation and sustainability.

The games we play: An arts-informed exploration of processes of non-participation and collaboration in PAR

Nienke Slagboom (Leiden University Medical Center)

Background

Inclusive health research aims to engage everyone with a seat at the table in addressing complex problems. In public health, Participatory Action Research (PAR) is particularly well-known for its collaborative and inclusive nature, aiming to facilitate the participation of stakeholders from so-called "under-represented" groups. However, collaboration between a diverse group of stakeholders in PAR studies can be complex. It is not uncommon to find disengagement in the very area where engagement is sought. For example, PAR studies in public health regularly struggle with the 'empty seat' phenomenon, where there is low or no participation from "under-represented populations". In addition, researchers might face the challenge of low or no collaboration between stakeholders. Up to date, the intricate dynamics of working together with families, experienced experts,

professionals, and policymakers have received limited attention in PAR studies. Therefore, to better understand the social and political meanings of non-participation or low collaboration, there is a need for frameworks to study and theorize micro-processes in inclusive health research.

This study adopts two approaches to explore micro-processes of non-participation and low collaboration. The first draws inspiration from Eric Berne's 'Games People Play' (1960), examining patterns in the way people (tensely) interact that often lead to more or less predefined outcomes. Instances of non-participation and low collaboration are studied by asking 'What games are played in PAR studies'? The second approach incorporates Robert Landy's concept of 'role lock', which examines how people repeatedly get caught up in the same, somewhat archetypal role, e.g., the bad guy, the witch, the emperor, limiting the positions from which one can respond to a situation.

Objectives

In order to understand micro-processes of non-participation and low collaboration, this study aims to map and analyze patterns of tense interactions in PAR studies within public health.

Methods

Building on interviews and participant observation in two public health PAR studies (conducted between 2015 – 2023), using qualitative content analysis, instances of non-collaboration and non-participation were mapped and analyzed. Further, leveraging an arts informed approach, the abovementioned instances of non-participation and low collaborations were 'translated' into games. Next, five instances of non-participation and low-collaboration were scripted into theatre dialogues, which were analyzed for roles, social dynamics and conflicts.

Findings

Preliminary analysis revealed common instances ("games") of non-participation and low collaboration in PAR studies. Competing world views, negotiations over power, voice, and positionality often led to immediate disengagement. Associations with governmental interference, racism and 'being on a mission to convert' limited possibilities for (inter)action. A common pattern in one PAR study reminded of a 'subversive' improvisation theatre exercise called "flip the seat". In this theatre game, Person A, ranking high in status and prestige—a rich, high-class businesswoman, the emperor—sits down on the only seat available in the park. Person B, a character with a lower status—a child, a clown—then steps into the park scene. The exercise: what can B do to get a hold of the seat? What can he or she do to flip the status, to immediately reverse the power dynamics? The seat is flipped when person A feels no other choice than to give up the seat—'you win'—a victory that is typically settled by the audience's laughter. In the abovementioned PAR study focused on health promotion, non-participation was likely underpinned by a protest against institutional indifference toward adverse social circumstances and a protest against the power of health institutes.

Discussion/conclusion

This study experimented with two arts-informed analytic lenses to explore subtle dynamics of non-participation and low collaboration in PAR studies. The findings underscore the importance of recognizing power differences, populations histories with institutions (including universities) and the premises of 'inclusive' methods in participative health research. An arts informed approach, which transforms a personal fieldwork experience to a story or a game, might be a useful approach to explore and reframe discussions on "hard to reach populations" and critically examine what (non)participation and inclusive entails.

5 July

5 July: 8:30 – 10:00

Mental Health, Regular session – Chair: Veerle Buffel – *Room K.101*

Intersectionality of gender, occupational social class, and migration status on mental health in the adult Spanish population: Comparison of three quantitative approaches.

Amaia Bacigalupe (University of the Basque Country), Antonio Moreno (University of the Basque Country), Mireia Utzet (Pompeu Fabra University)

Introduction

Literature has largely shown relevant social inequalities in mental health, according to which women, socioeconomically disadvantaged populations, and migrants or ethnic minorities suffer higher rates of poor mental health. However, these social inequalities rarely impact mental health in a unilateral way, and in consequence, intersectionality has been recognized as an important framework for public health to identify complex nets of inequalities in health. There exist many methodological approaches to quantitative methods for intersectional analysis and none of them is free from limitations and methodological challenges. The objective of this study was to analyze social inequalities in mental health in Spain from an intersectional perspective, comparing three qualitative methods.

Methodology

We used data from the Spanish National Health Survey (SNHS) in 2017 and 2012 with a total effective sample size of 40,441 people aged 18 and over (women, 53.0%). The SNHS is a repeated cross-sectional survey representative of the Spanish adult population, with a three-stage sampling method. Occupational social class was simplified into 3 groups as higher (18.3%), middle (18.9%), and lower (62.8%) social class according to previous studies (Domingo-Salvany et al., 2013). Migration status was self-reported and classified as native (i.e., born in Spain, 90.8%) or immigrant (9.2%). Mental health symptoms were measured by using the 12-question General Health Questionnaire (GHQ-12) (Goldberg et al., 1997). The GHQ-12 assesses the individuals' overall mental health status by means of 12 questions in 4-Likert scale with a final score by a bimodal procedure (0-0-1-1) that ranges from 0 to 12. We then dichotomized the GHQ-12 score following previous studies (Anjara et al., 2020) into having a good (<4, 85.5%) or bad (≥4, 14.5%) mental health status. Three logistic regression models were run: 1) a main effect model with only gender, social class, and migration as independent variables (as reference model); 2) a cross-classified strata (12 categories) model; and 3) a main effect model with gender, social class, and migration interaction terms. All models were adjusted by age. We also estimated the AUC-ROC (Area Under Curve-Receiver Operating Characteristic) to compare the classification accuracy between main effect model with cross-classified and interaction term models. Reference groups were women, lower social class, immigrant, and bad mental health. Rstudio version 4.3.1 (Rstudio, Inc., Boston, MA, USA) was used to run the analysis.

Results

Both the main effect and the interaction term model showed that men and higher social classes were more likely to report better mental health, while migration status was not significant. In addition, there was no 3-way nor 2-way interactions of social class, gender, and migration status in the interaction term model. The cross-classified model complementarily showed that high-social class native and immigrant men presented the highest odds of better mental health, followed by middle-social class native and immigrant men. Higher-class women and lower-class men (native and immigrant) also showed higher odds of reporting better mental health, compared with lower-social class immigrant women. The overall classification accuracy was similar between main effect model (AUC-ROC: 0.6160) and cross-classified and interaction term model (AUC-ROC: 0.6164).

Conclusion

In summary, in our case, being men and of high or middle social class were independently associated with better mental health, but without any triple nor double jeopardy. No independent association was found by migration status. As such, the main effect, cross-classified, and interaction term models presented comparable accuracy performance. Additionally, cross-tabulated model showed specific strata differences among social groups: compared with lower-social class immigrant women, all intersectional strata were more likely to describe better mental health, excepting middle-social class immigrant women and lower-social native women. Finally, study limitations refer to cross-sectional data from the SNHS and self-reported mental health symptoms by the GHQ-12 questionnaire.

Depressive symptomatology from a network perspective: Differences in the experience of symptoms by social position

Eugenia Alcalde (INSERM), Alexandra Rouquette (INSERM; CESP), Emmanuel Wiernik (Université Paris Cité, Paris-Saclay University, Université de Versailles Saint-Quentin-en-Yvelines, INSERM), Laurent Rigal (INSERM; CESP)

Background

While social inequities in depression are well-documented, the symptom experience across social positions remains less studied. Notably, research is scarce on individual-level factors, such as the experience of symptoms influencing the self-recognition of depression and the diagnosis process across social positions. Socially disadvantaged groups may intentionally or unintentionally conceal their symptoms for long periods or simply do not perceive the need for help, which is why we considered important to explore which symptoms are involved in these two distinct stages (self-recognition and diagnosis).

Aims

This study examines the connections between depressive symptoms and self-recognizing a depressive episode, on the one hand, and clinical diagnosis, on the other hand, by three social position indicators.

Methods

We analyzed baseline data from a population-based cohort of adults living in France, grouping participants by three indicators: education, financial difficulties, and occupation, and stratifying by sex. Utilizing a psychometric network approach, we estimated 24 networks. Nodes corresponded to the 20 CES-D items and one external variable, either 'Limitations due to depression' or 'Clinical depression.' Comparisons between socially disadvantaged and advantaged groups across the three social indicators were made in terms of network structures, global strength, and edge weights involving symptoms and both external variables.

Results

The study included data from 201,952 participants. Individuals in lower social positions exhibited higher rates of depressive-related variables. Four depressive symptoms emerged as crucial, being linked both to 'Clinical depression' and 'Limitations' across all social positions. Socially disadvantaged groups had denser networks, suggesting an increased risk of the network becoming active (i.e. experiencing depression). Some of the tests comparing network structures according to social position were significant, suggesting differences in the symptom activation chains. Connections between each external node and 'Felt depressed' and 'Could not get going' were non-invariant in educational and financial-based networks.

Conclusions

Socially disadvantaged groups had denser depressive networks, which, clinically, might translate into more severe and active symptomatology. To our knowledge, this study is the first to investigate the relationships between depressive symptoms with a previous diagnosis of depression and depressive symptoms with the self-recognition of limitations due to depression from a network perspective. Some of the connections were socially differentiated and gendered. Findings highlight four depressive symptoms ('Could not shake the blues', 'Felt

depressed', 'Everything was an effort', and 'Life was a failure') likely to play a key role in the experience of depression across all social positions. Connections between symptom 'failure' and both external nodes tended systematically to be stronger in socially advantaged groups, which may underlie within-group mechanisms. If success and failure are feelings commonly attributed to individuals (i.e., promoted by meritocracy values) in developed countries then socially advantaged groups might perceive more feelings of failure whenever experiencing difficulties simply because these struggles do not meet group expectations. Other insights from specific symptoms could be used for improving depression care among disadvantaged populations.

This work should be interpreted in light of its limitations. First, we used the CES-D items as proxies of symptoms presented in consultation with clinicians and from which they substantiated diagnoses. Nevertheless, items capture only a limited experience of depressive symptomatology and may fail to reflect other symptoms arising in consultation.

Counteracting complex intersectional self-stigmatization through empathetic group work

Helena King (The Open University)

Introduction/objective(s)

People living with HIV (PLHIV) can lead deeply complex lives often shaped by profound inequality. Intersecting stigmatized identities, socioeconomic factors such as unemployment, and comorbidities contribute to heightened vulnerability compounded by living with a hidden disability. Mental ill health is common and has been linked with internalized stigma. Whilst effective psychosocial support can help PLHIV mitigate the effects of stigma, in the UK access to mental/social support is variable and there are no well-established interventions that target internalized stigma and multifaceted biopsychosocial issues associated with HIV. This paper provides insights from a peer-led 'retreat' intervention which offers PLHIV opportunities to build support networks and explore the diversity of challenges they face in a safe, confidential environment. The study project sought to understand the therapeutic processes inherent to retreats as a way of improving our understanding of complex internalized stigma.

Method

A key principle for this study was for PLHIV to design, implement, monitor and evaluate the intervention from its inception. This ethically sensitive coproduced project obtained ethical approval from The Open University Human Research Ethics Committee HREC reference number 4315. An intervention was co-delivered across four 2.5-day residential retreats (>120 participants over 36 group sessions) and qualitative research data gathered via participant observation/ note-taking and audio-recorded/transcribed i) group sessions (x2) and ii) in-depth semi-structured interviews (x10). Transcripts and notes were thematically coded through an abductive iterative process over the course of the 18-month long study.

Results

Research findings revealed the social context for members' participation including social isolation, trauma and discrimination. The core features and healing principles which emerged included peer-leadership, trust, openness, group dynamics, self-reflection and bonding processes.

Discussion

Findings are discussed with reference to theory on biographical disruption, empathy and humanistic psychology.

Mental health and the intersection of social inequalities and experienced discrimination among university students in Germany

Laura Pilz González (Charité – Universitätsmedizin Berlin, corporate member of Free University of Berlin & Humboldt University of Berlin), Enrique Alonso- Perez (Charité – Universitätsmedizin Berlin, corporate member of Free University of Berlin & Humboldt University of Berlin), Jennifer Lehnchen (Charité – Universitätsmedizin Berlin, corporate member of Free University of Berlin & Humboldt University of Berlin), Julia Burian (Bielefeld University), Zita Deptolla (Bielefeld University), Eileen Heumann (Charité – Universitätsmedizin Berlin, corporate member of Free University of Berlin & Humboldt University of Berlin), Hürrem Teczan-Güntekin (Alice Salomon University of Applied Sciences), Katherina Heinrichs (Charité – Universitätsmedizin Berlin, corporate member of Free University of Berlin & Humboldt University of Berlin), Christiane Stock (Charité – Universitätsmedizin Berlin, corporate member of Free University of Berlin & Humboldt University of Berlin)

Introduction

Discrimination poses a significant threat to the health and well-being of higher education students. Research has highlighted the disproportionate impact of perceived discrimination on the mental health of students in disadvantaged social dimensions. While certain characteristics, such as sex/gender and/or race/ethnicity, potentially aggravate this association, there is limited understanding of the intersectional experience of discrimination in higher education as contexts of social inequality and its consequences for students' mental health. Our study examines the intersection of social inequalities with experiences of discrimination among students in Germany, to explore differences in mental health across such intersectional strata.

Methodology

Using data from the cross-sectional project “Study Conditions and Mental Health of Students” (StudiBiFra), collected at 13 German higher education institutions between June 2021 and March 2023, we performed a Multilevel Analysis of Individual Heterogeneity and Discriminatory Accuracy (MAIHDA). The data collection was carried out with the “Bielefeld Questionnaire on Study Conditions and Mental Health” and was funded by the German Social Accident Insurance (DGUV).

We first explored the associations between experiences of discrimination and mental health indicators of depressive symptoms, cognitive stress symptoms, and exhaustion, each of them measured as a binary outcome derived from several validated items. Further, students were nested in 48 intersectional strata, defined by the combinations of gender, first academic generation, family care tasks, and perceived experiences of discrimination by lecturers only, fellow students only, and both sources. We explored the variation on the three mental health outcomes across intersectional strata, adjusting for age and the specific higher education institutions.

Results

Among the 14,592 included participants, a majority of 66.92 % identified as female, while 1.82 % identified as gender diverse. Additionally, 37.94 % of participating students reported being the first generation in their family to attend higher education, and 13.35 % had family care tasks alongside their educational responsibilities. In terms of perceived discrimination, 10.11 % of participants reported experiencing discrimination from lecturers, 5.40 % from fellow students and another 5.17 % from both sources.

The proportion of the total variance explained by strata affiliation is 5.92 % of the variance in depressive symptoms, 6.20 % in cognitive stress symptoms and 5.71 % in exhaustion, revealing a fair discriminatory accuracy according to grading standards in social epidemiology (VPC of > 5 to ≤ 10). Differences in mental health outcomes across intersectional strata were fully explained by additive effects of the social categories included, highlighting their influential role in explaining the observed associations and variability in mental health outcomes across strata.

In particular, discrimination perceived from both sources - lecturers and fellow students - had the most detrimental association; students experiencing double discrimination had 2.65 times the odds to experience depressive mood (95% CI: 2.20-3.20), 2.65 times the odds to experience cognitive stress symptoms (95% CI: 2.20-3.19), and 2.40 times the odds to experience exhaustion (95% CI: 2.00-2.90) compared to students with no experience of discrimination.

Students who identified as gender diverse had a 2.53-fold chance of depressive symptoms (95% CI: 1.83-3.49), a 2.95-fold chance for cognitive stress symptoms (95% CI: 2.15-4.05), and a 2.42-fold chance for exhaustion (95% CI: 1.76-3.32) than male students. Additionally, being a first-generation student was associated with slightly increased odds for all three mental health outcomes compared to students from academic households (depressive symptoms: OR = 1.25; 95% CI: 1.15-1.37; cognitive stress symptoms: OR = 1.17; 95% CI: 1.08-1.28; exhaustion: OR = 1.25; 95% CI: 1.15-1.37). Those balancing family care tasks experienced higher odds only for exhaustion (OR = 1.35; 95% CI: 1.19-1.55) compared to their peers without care responsibilities.

Our study found no statistically significant evidence of intersectional (multiplicative) interaction effects for any of the three mental health outcome measures, with the between-strata becoming zero in the main effects models. However, our findings unveil significant associations between perceived experiences of discrimination and adverse mental health outcomes among higher education students in Germany.

Conclusion

This study underscores the profound associations between experienced discrimination and the mental health of higher education students in Germany, highlighting the nuanced intersections of gender, first academic generation, family care tasks and perceived discrimination. In doing so, our findings underline how dimensions of social inequality are negatively associated with mental health. The results call for urgent attention and interventions within higher education institutions. Adopting an intersectional lens is a first step towards unveiling and decomposing inequalities.

Understanding ADHD-related stigma: A gender analysis of key stakeholder perspectives

Marlies Visser (Athena Institute, Free University of Amsterdam), Ruth Peters (Athena Institute, Free University of Amsterdam), Marjolein Luman (Free University of Amsterdam)

Introduction

Children and adults with attention-deficit/hyperactivity disorder (ADHD) may encounter negative beliefs, attitudes and behaviors associated with their condition, collectively referred to as stigma. Mental illness stigma has been conceptualized as stereotypes (cognitive responses), prejudice (affective responses) and discrimination (behavioral responses) relating to one's devalued identity (Dovidio et al., 2010; Stangor, 2009). Various factors may underly ADHD-related stigma, including the large heterogeneity in aetiology and presentation, absence of diagnostic instruments perceived as more objective and negative media coverage (Baeyens et al., 2017; Hinshaw et al., 2022; Quinn and Madhoo, 2014), all facilitating distrust of the concept of ADHD. Further, ADHD is often misunderstood, as there is a large focus on hyperactive/impulsive behavior over inattentiveness and a predominant focus that ADHD is particularly related to boys (Horton-Salway and Davies, 2018).

Gender has been theorized as a set of everyday behaviors or performances, conditioned and regulated by society (Butler, 1990). Gender performativity suggests that individuals 'do' or 'perform' gender, by conforming to societal norms and expectations associated with social constructions of masculinity or femininity (i.e. gender roles and norms) (Butler, 1990). Studies have shown that gender influences health beliefs and attitudes and one's management of health conditions, and may thus influence health outcomes (Saltonstall, 1993; Williams, 2000). Gender may influence how individuals with ADHD construct, exert or protect their femininity or masculinity in a given situation and may thus influence one's coping with ADHD and/or stigma.

Among the growing body of literature on ADHD-related stigma, few studies have qualitatively explored the perspectives of various key stakeholders, with limited attention to gendered stigma dynamics. This study explores stakeholder perspectives on ADHD-related stigma and manifestations in the daily life of children and young adults with ADHD, and explores the role of gender.

Methodology

Respondents were recruited and data was collected between December 2022 and July 2023. A total 24 respondents participated in seven focus group discussions, including 14 young adults with ADHD (18 – 30 years), three parents of children with ADHD, four mental health professionals and three primary school teachers. The FGDs followed a semi-structured FGD guide and comprised 3 discussions. Data from discussion 2, which included questions regarding ADHD-related stigma and manifestations across various contexts including educational, professional, social or family contexts and gender differences, were analyzed for this paper. The transcripts were coded using Atlas.ti 22 and Excel, following thematic content analysis. All subcodes were organized in two overarching categories; ‘stereotypes and prejudice’ and ‘stigma manifestations’, in line with the research questions.

Results

First, the analysis revealed overarching themes encompassing both overt and more subtle stereotypes and prejudice, including: (1) rejection of ADHD; (2) viewing ADHD as a deficit; (3) misconceptions stereotyping or trivializing ADHD, and (4) balanced and inclusive beliefs and attitudes. Some of the stigmatizing responses are subtle (e.g., ‘just try a little harder’) and in some cases are well-intended or implicit (i.e. based on unconscious beliefs, attitudes and behaviors).

Second, stigma manifestations included public ignorance, skepticism, rejection, a lack of appropriate support, and discrimination, facilitating negative self-concept. More specifically, young adult women reported altered identity development, masking and loneliness, whereas young adult men reported internalized negative attributions, nondisclosure and reduced help-seeking behaviors.

Conclusion

Study findings reveal both overt and more subtle expressions of ADHD-related stigma. These, at times hidden and underestimated, expressions can be understood as microaggressions (Pierce, 1974; Sue et al., 2010) and pose a risk to the health and wellbeing of individuals with ADHD (Mueller et al., 2012). Our results indicate that gender norms influence stigma expressions, suggesting that feminine and masculine norms shape stigma. Manifestations of negative self-concept among women, including altered identity development and masking, may be informed by negative judgements related to gendered understandings of ADHD and (a fear of) diverging from feminine norms (e.g., impulsivity/disorganization). Men’s hesitancy to disclose their diagnosis or seek help may be coded by self-reliance and independence and shame or judgement due to not achieving these masculine norms.

This study underscores the necessity for research and interventions to address implicit gendered dynamics that fuel ADHD-related stigma and impact ADHD diagnosis and mental health care services. This to better support the diverse needs and strengths of individuals with ADHD.

Technology and Health, Regular session – Chair: Veronica Moretti - Room K.102

How and why people use mobile phones near bedtime and in bed

Dana Zarhin (University of Haifa)

Introduction

Prior studies have examined the impact of smartphone use on sleep, focusing on the negative impact of phone

use on sleep outcomes. Additionally, there is a growing interest in the interface between mobile phones and society, with multiple studies showing how mobile phones have reconfigured how people experience and understand the world as well as how they act in it. Nevertheless, despite the widespread use of mobile phones before bedtime and in bed, there remains a significant gap in our understanding of the specific ways in which these devices are used and the reasons behind this usage.

Methodology

The current research addresses this gap by exploring how and why people mobile phones before bedtime and in bed. It draws on data from sleep diaries and in-depth interviews with 66 employed Israelis aged 40-60. This group is diverse in terms of gender, ethnonationality, socioeconomic status, religion, and sleep quality. Participants were asked about their mobile phone use before bedtime and in bed and its perceived effects on their sleep.

Results

The results show that the human–mobile phone sleep assemblage generates agentic capacities that allow individuals to engage in a digitally enabled form of what I call *sleepful sociality* – a sociality marked by sleep. Through the use of mobile phones, individuals create, maintain and/or detach from social relations and fulfil social obligations near bedtime and during sleep, while also trying to facilitate and protect their own and their bed partner’s sleep. Specifically, phones served four key functions:

1. Participants used their smartphones as alarm clocks to wake up on time for work and caregiving duties. Users kept devices nearby to quickly silence alarms and avoid disturbing bed partners.
2. Participants stayed connected to the outside world by seeking information and communication. They regarded bedtime as their 'personal time', which they could dedicate to themselves and their interests. Nighttime was an opportune time for this, as the usual daily burdens lessened and sociocultural norms allowed for a certain withdrawal from social obligations. The majority of respondents noted that they pursued these activities at their own pace, which helped slow down time and often induced sleep.
3. When feeling anxious, participants used their phones as a form of 'escapism' to distract themselves from disruptive thoughts. Interestingly, in these narratives, individuals considered mobile phones as friends of sleep rather than foes.
4. Some social obligations, like the need to remain available to family members, persisted around sleep. Therefore, many respondents chose to keep their phones turned on throughout the night, with sound and notifications enabled, as a means of staying connected to their loved ones. This is particularly helpful for receiving reassuring messages from family members or children while they are out at night. By doing so, they can communicate without fully waking up, which helps protect their quality of sleep. Mobile phones serve as a vital lifeline to loved ones, offering comfort and security during times of separation.

While the phones often facilitated sleep, the affordances of the device sometimes hindered sleep. The respondents reported that they were occasionally tempted to stay awake and delay sleep longer than intended. Their phones sometimes drew them in against their wishes, keeping them alert instead of somnolent.

Conclusion

The analysis provides insight into how technological transformations create new opportunities for being social. Specifically, this study sheds light on the form of sociality that takes place in and around sleep, a necessary examination to enrich the understanding of what it means to be 'social'. This study discusses a specific type of sleepful sociality, one enabled through human–mobile phone entanglement. As the analysis shows, intra-actions between respondents and their mobile phones allow respondents to both participate in and withdraw from a range of social relations and obligations.

As people sleep with and through phones, the devices alter their sleep experiences and management. These technologies may continue to reshape our sleep and expectations of it. Although respondents appreciated the newly gained capacity for constant connectivity, it is possible that with time, this capacity will further undermine a valuable right – the right to disconnect. Further research should explore sleepful sociality and its sociocultural patterning across various groups.

Living better at home: RCT evidence on the impact of social technology on elderly's well-being

Kristoffer Eikemo (Oslo Metropolitan University)

Background

With the demographic shift towards an aging population, frail elders in many countries now receive long term care (LTC) in their own homes, rather than in nursing homes. While this strategy may enhance health sector effectiveness, it carries the risk of increased loneliness and insecurity among the elderly. These factors can significantly impact the quality of life for the elderly population. Further, as receiving LTC at home requires a certain level of self-sufficiency and resources, it may accelerate the already increasing social inequalities in health, as those already more susceptible to loneliness are disproportionately affected. In response to the 'loneliness epidemic', both researchers and international organizations have emphasized the potential of welfare technology, and several studies have been conducted on such technology, providing valuable insights into its potential benefits and impacts. However, social welfare technologies have received limited attention, despite the known correlation between social contact, quality of life, and general health. To our knowledge, existing studies on this topic have either been relatively small in scale or lack a broader, societal, focus. Specifically, they fail to consider how these technologies impact different socioeconomic groups among the elderly.

Objectives

In this context, the study aims to investigate the impact of a social communication technology, Komp, on the living conditions of the elderly living at home, to enhance the scientific foundation for policy making within welfare technology and elderly care. Our research question is: Can the use of social welfare technology improve social contact and quality of life among elderly people receiving LTC at home? We further investigate whether the potential impact varies across socioeconomic groups. Based on previous literature on the role of socioeconomic status (SES) in the take-up of technological innovations, we hypothesize that Komp has a greater impact on individuals with higher SES. However, given that Komp is designed for those with lower technological competence, this differential impact might be less pronounced, as compared to other technologies. This consideration underscores the importance of examining the potential equality-enhancing effects of the technology.

Methods

The research project was designed as a randomized control trial (RCT). The sample comprises individuals who (i) are over 67 years old, (ii) live in their own home (in three districts of Oslo, Norway), (iii) have a decision on home nursing care, and (iv) have functional problems as measured by the home care services. These make up 1200 individuals, of which 557 randomly selected individuals are offered Komp (the intervention group). Those not offered Komp will make up the control group. A survey was conducted across the two groups, where we asked about their media and communication habits, perceived safety in their own home, general quality of life, and their social participation. The survey data was subsequently linked with the district's health journal system, usage data from Komp, as well as administrative data from Statistics Norway. This comprehensive dataset allows us to investigate whether a potential effect of Komp varies according to user characteristics, their family, or the usage of Komp.

Results

While data from the elder survey are not yet available, preliminary insights have been obtained from a concurrent survey targeting their next of kin. They reported that they believed Komp improved social contact

and the quality of life among the elderly. This gives us an indication of what results we can expect from the elder survey, which will be ready for analysis in February.

Conclusion

Should the results imply increased social contact and/or improved quality of life for the elders, it would underline the potential of social technology in improving elderly care and preventing loneliness. However, the potential variation of the effects across socioeconomic groups will need careful consideration. If the hypothesis holds, the challenge then lies in mitigating this discrepancy to ensure that the benefits of social technology in elderly care are reaped by all, not just the most resourceful. On the other hand, if the technology proves to be equally beneficial across socioeconomic groups, or even more so for the least resourceful, it could serve as a valuable tool in reducing health inequalities. In any case, the study emphasizes that the impact of social technology cannot be adequately assessed without considering the socioeconomic context.

Intersections of personal and environmental wellbeing: Experiences of reusable menstrual product technologies

Malissa Kay Shaw (University of Health Sciences and Pharmacy in St. Louis),

Introduction

Menstruation is a physiological process experienced by nearly half the world's population at some point in their lives. Despite its prevalence it has been understudied by both the medical and social sciences. Menstrual products – technologies traditionally developed to help menstruators conceal their menstruation in order to more fully participate in capitalist society (e.g., Martin 1987) – are also an under researched area of women's health.

Notwithstanding this lack of research, two areas of concern have been raised about single-use menstrual technologies. Since the 1970s, feminist activists have raised concerns about health risks associated with mainstream menstrual products both during use and production (e.g., Bobel 2010). More recently, trepidations have been raised about the environmental aspects of menstrual products, specifically the substantial waste and pollution they produce and the energy and resources required for their production (e.g., Davidson 2012). Such concerns have helped drive the development and promote the use of reusable menstrual products – menstrual technologies that are marketed as more environmentally and health friendly, and as giving menstruators greater agency by providing alternative options to traditional single-use products. Menstrual cups, an insertable device that captures rather than absorbs menstrual blood, are one such option. In this paper I will explore the ways in which notions of personal and environmental health are entwined in narratives about menstrual cup usage, and how, for some menstruators, using a menstrual cup has created new intersections between personal wellbeing, environmental engagement, and technologies.

Methodology

This paper is part of a larger project that explores the multifaceted relationships between producers, users, menstrual technologies, and society to develop a better understanding of the ways new technologies transform notions and experiences of menstruation. This portion of the study consisted of qualitative interviews with menstrual cup users, menstrual activists, menstrual cup companies and distributors, and a gynecologist in Colombia. Interviews were conducted between February and August of 2022. All participants consented to participate in this study. The thematic analysis of the data is ongoing.

Results

Environmental concerns and the desire to reduce waste were the primary reasons many menstruators chose to try a menstrual cup. However, benefits to personal health and wellbeing were often experienced after cup use was adopted rather than anticipated. While all menstrual cup users recognized that their menstrual waste was reduced by using a cup, there was more variation in the extent to which health benefits were experienced. For

some, the materiality of the cup, the same properties that make the cup reusable, improved their menstrual experience by reducing irritation and odors. Other menstruators acknowledged the biocompatibility of the cup's material, perceiving it to be less toxic and potentially contaminating than single-use products. Participants often specifically referenced reducing the risk of toxic shock syndrome. Additionally, many menstruators acknowledge that the cup's collection rather than absorption of blood allowed for new forms of engagement with their menstruation and the development of bodily awareness created through monitoring their blood (its consistency, volume, and odor), a process some felt could give them insight into their overall health.

The connections made between environmental health and personal health varied across participants. Some menstrual cup users presented the two as distinct narratives, but used similar examples and framing in discussing both. Other users perceived a direct correlation between the two and articulated this explicitly by combining their narratives about bodily health and environmental practices. Interestingly, a few participants appeared to feel that using a menstrual cup brought them closer to a natural form of caring for themselves and the environment by, for instance, collecting menstrual blood and using the blood to nourish plants.

Conclusion

While the thematic analysis of the data is ongoing, narratives relating to health, wellbeing, the environment, and sustainability proliferate and often intersect. This provides important insights into how new technologies may be instrumental in cultivating new, critical conceptualizations of health and wellbeing in a context where these issues have largely been neglected. Moreover, these intersecting narratives present opportunities for exploring notions of wellbeing that go beyond the present self to include future notions of the self, and also the self in relation to environment wellbeing.

Producing 'facts' about older people: InterRAI assessments in social context

Pauline Norris (University of Otago), Sarah Colhoun (University of Otago), Emily Keddell (University of Otago), Esther Willing (University of Otago), Donna Cormack (University of Otago)

Introduction

Ethnic and other inequities in access to medicines have been documented in New Zealand, and a range of potential barriers to access identified. These include affordability, lack of transport, geographical distance, and acceptability of services. Existing research has tended to focus on one barrier, rather than how barriers interact and intersect, and how they are experienced by consumers.

Methodology

We carried out a longitudinal qualitative study to explore lived experience of access to medicines. We recruited 21 households from groups that may be at risk of poor access (Māori, Pacific, former refugee, Pākehā (New Zealand European) on low incomes). Households were eligible if their members mainly belonged to one of these groups and someone in the household took medicines regularly. Participants were recruited through community organizations and networks, and healthcare providers. For example, one participant was recruited at a food bank, one through a service for former prisoners, two were recruited through community pharmacies, and primary health organizations assisted in contacting refugee participants. We followed participating households for approximately 12 months, with repeated interviews, phone conversations, text messages and observations. We asked about people's lives and how things were going, focusing on healthcare and medicines, within the context of people's lives.

Results

Many of our participants faced social disadvantage and had physical health problems. Some also had mental health problems. Often their lives were characterized by a sense of "too much going on" and this formed the backdrop to issues with medicines. Obtaining required medicines was just one of many issues to be faced.

There were many affordability problems: most participants had to pay to obtain a prescription from a general practitioner (either by visiting or ordering a repeat prescription), as well as prescription charges. It was clear that charges could directly prevent access, but also potentially eroded relationships with healthcare providers, reducing acceptability of services. There could be confusion about charges, and when they were perceived as unreasonable participants felt aggrieved. At the time of the study, most pharmacies charged a fee for collecting medicines, and this drove some participants' choice of pharmacy. Some felt forced to choose between cost and physical accessibility or quality of care.

Refugee participants faced significant barriers: they were unfamiliar with and dissatisfied with healthcare in New Zealand, faced seemingly insurmountable communication barriers, and many did not trust the medicines they were prescribed. Despite the presence of an interpreter in general practice consultations, there were many misunderstandings and some refugee participants felt they were treated badly because of their refugee status. Interpreters were not available in pharmacies, meaning refugee participants could not ask questions about their medicines or discuss any concerns.

Many participants experienced mistakes in the ordering or dispensing of their medicines, and the responsibility for sorting these out fell on participants. This took time and energy which participants did not always have.

Conclusions

Our results provide insight into overlapping and interacting barriers to medicines access faced by people experiencing social disadvantage in New Zealand. Since the study, affordability has improved somewhat with the elimination of some prescription charges, but many other barriers remain.

Combining Employment and Informal Care for the Aged, Thematic session – Chair: Karl Krajic & Thomas Geisen - Room K.103

Combining informal care for the aged with employment – Necessarily a double burden with negative health effects?

Charlotte Dötig (FORBA, University of Vienna), Viktoria Quehenberger (FORBA), Karl Krajic (FORBA, University of Vienna)

Introduction

Informal Care is the dominant model of care for the aged in most European countries. Welfare state concepts for the aged in most countries assume, that care for aged persons in principle is a family duty. This privatization of care responsibilities goes along with a lack of recognition that informal care can bring along several “penalties” (Sue Yeandle): Economic losses, social exclusion, and losses of mental and physical health. Several of these losses are related to many informal carers reducing or quitting employment – a reaction that welfare state policies in many countries so far do not try to prevent, but rather encourage to reduce or leave employment and thus contribute to negative social consequences, especially for women who form the majority of carers.

Concerning health effects, combining employment and informal care for the aged seems to be considered as a double burden situation. Quitting one of these two duties is considered as a possible relief. This rather simplistic perception on informal carers and possible solutions to resolve a double burden situation seems rather to be fostered by welfare state policies – at least in several countries like Austria.

Concerning the situation of those who try to continue employment while accepting informal care duties, there is rather little systematic knowledge, at least in Austria. We have some information how many employees are actually combining work and informal care. In Austria, about one third of informal carers in working age is combining work and employment. Looking at this large numbers, surprisingly little attention to the specific needs of those who attempt combining has been paid. We know very little about the practices of carers, colleagues and

management at the workplace level, and we know very little about their perception of specific health risks and chances, which go along with combining.

Methodology

The presentation is based on results of the project Combining Employment with Care for the Aged – COMBECA. This is a cross-national, multi-perspective study in Austria and Switzerland (FORBA Vienna and FHNW School of Social Work Olten funded by FWF and SNF) on the relevance, practices, and effects of combining work and family care in the workplace context.

The paper uses a multi-dimensional health concept, as proposed by Jürgen Pelikan (2007, 2009) in the context of health promotion in organizational settings, including perspectives on physical, mental and also social health. The presentation reports results on perceived health risks of carers as well as perceived positive health opportunities, in particular chances to stabilize or even increase specific aspects of health, when successfully combining,

The analysis is based on 14 mixed-methods case studies in companies in Austria and Switzerland. One part of the data is based on qualitative interviews, the other part consists of quantitative survey of employees. Results are interpreted in the context of the national welfare system and its support measures.

Results

First results indicate that certain practices of carers but also management seem promising to manage stress levels and help employees to successfully combine work and informal care and therefore retaining positive effects of inclusion in working life like income, a higher level of age pensions, chances for professional success and intrinsic benefits of work and inclusion in workplace and professional networks. Analyzes also indicate that welfare state provisions could be improved to increase chances to successfully combine employment and care with potential positive health effects.

Conclusion

Results clearly indicate the relevance of combining research perspectives on the carers as persons, on the organizational level of workplaces and on welfare state provisions supporting (or not supporting) informal carers especially when trying to combine employment and care as well as the usefulness of cross-national or international research.

Negative health and quality-of-life effects of caring for a spouse: a population-based study in Finland

Katja Ilmarinen (National Institute for Health and Welfare), Anna-Mari Aalto (National Institute for Health and Welfare), Sari Kehusmaa (National Institute for Health and Welfare), Marko Elovainio (National Institute for Health and Welfare), Päivi Sainio (National Institute for Health and Welfare)

Introduction

Informal caregivers take care – to a significant extent – of people with impaired functioning in addition to society's responsibility for care. Informal caregivers are considered an important care resource and partners to the public sector when the number of people needing help increases in the future, and when the goal is for the elderly to live in their own home for as long as possible.

Providing care causes both positive and negative effects on the caregiver's life. The caregiver can feel a sense of appreciation for important work, experience an increase in family cohesion, and get a sense of purpose in their life from care (Toljamo et al. 2012; Yu et al. 2018; Pysklywec et al. 2020). The caregiver may also be stressed, lonely, feel inadequacy and face health problems and financial difficulties, and they do not use the services according to their needs (Pinquart & Sörensen 2003; Bom et al. 2018; Peel & Harding 2019; Van Aershot et al. 2021).

There is only a little recent population-level knowledge on the well-being of informal caregivers in Finland. The purpose of the present study was to learn more about Finnish spousal caregivers' health and well-being. In addition, unmet needs of caregivers for health care and social services were examined. The results aim at helping decision-makers to develop and provide support so that health, well-being and resources of those caring for their loved ones is preserved and strengthened.

Methodology

In the present study, health, well-being and quality of life of those who care for their spouse at home were investigated, as well as caregivers' experience of receiving health care and social services. Study utilises data from a cross-sectional, population-based FinSote-survey in 2020. The survey is based on a random sampling design, which is stratified by age and region and drawn from the Digital and Population Data Services Agency Finland. The survey was sent to 48,400 people over 20 living in Finland. 28,199 responses were received. Of those, around 3000 respondents were considered as informal caregivers for their spouses. Comparing the rest of the population, the analysis involved the caregivers' background factors (e.g. age, gender, education, need for income support, place of residence) as well as factors related to well-being (e.g. perceived quality of life and state of health, psychological stress, participation activity, loneliness). In addition, some health risk factors were examined. Differences related to well-being, health, and unmet needs for services between those helping their spouse and the rest of the population were analyzed using logistic multivariate models.

Results

Those caring for their spouse reported more psychological stress than others, perceived their health weaker, and also more often than the rest of the population had some serious functional limitation. Those helping their spouse also felt their quality-of-life was clearly lower than the rest of the population, and this difference was not explained by differences in socio-demographic background factors or health. Those caring their spouse also felt more often than the rest of the population that they did not receive enough social and health care services. They also had other more general health risks, such as less participation in leisure activities, too little exercise and difficulty getting enough sleep. A positive finding was that loneliness was not experienced more commonly than others.

Conclusion

Those caring for their spouse seem to have many risk factors that weaken their well-being, which can also endanger the safety of the caregiving relationship. It is important to identify those caregivers who should be offered support and services at a sufficiently early stage.

Health effects on employees who provide informal care for older people

Thomas Geisen (University of Applied Sciences and Arts Northwestern Switzerland), Andrin Altherr (University of Applied Sciences and Arts Northwestern Switzerland)

Background

Combining employment with informal care affects various areas of life, which can be summarized under the following terms: the workplace environment, work-life balance, mental and physical well-being, and commitment. While employment can serve as a resource for working caregivers by providing participation in social life, this positive effect usually diminishes over time (Bernard & Phillips, 2007). Working informal caregivers can face several particular challenges at the workplace such as constantly having to negotiate agreements (Schneider, Häuser, Ruppenthal, & Stengel, 2006), unsupportive colleagues and supervisors, and a generally conflict-ridden working environment (Bernard & Phillips, 2007). Furthermore, a shortage of staff and recurring work overload can lead to role conflicts, which are exacerbated by difficult family dynamics, not having enough time for recreation, friends (ibid., Gaugler et al., 2018), partners and other family members, and can reduce the quality of life (Reuyß, Pfahl, Menke, & Rinderspacher, 2012). Common outcomes of combining employment with

informal caregiving include negative impacts on well-being and mental and physical health (Arksey, 2002; Schneider et al., 2006).

Methodology

In the COMBECA research project (2021-2024; funded by FWF and SNSF) company case studies (n=9) were conducted in Switzerland using a mixed-method research design. In the qualitative component guided interviews with CEOs, HR managers, Heads of departments and team leaders (n=4-6 interviews) and , as well as focus group interviews with employees who provide care for older people (n=1-2) were conducted. The interviews were recorded, transcribed, and analyzed according to the Grounded Theory (Charmaz, 2014) approach. In the quantitative part of the case studies an online survey was conducted and disseminated to all employees of the company. The survey includes question regarding informal care duties, organizational social capital (Badura, Greiner, Rixgens, Ueberle, & Behr, 2013), work-life balance, sociodemographic characteristics and health outcomes. A multivariate analysis is applied to assess the relationship between these variables and look at differences between non-caregivers and different groups of informal caregivers, with a focus on health outcomes.

Results

Working informal caregivers report a poor work-life balance and deteriorated mental and physical health because of their double or triple duty. However, supportive superiors and colleagues as well as caregiver-friendly policies can improve work-life balance and reduce negative health outcomes. The multivariate analysis confirms the qualitative findings and gives more insights regarding the moderating role of organizational social capital, gender, age, and socioeconomic status on health outcomes of informal caregiving.

Conclusion

Organizational attitudes, practices and policies affect the reconciliation of employment and informal caregiving. Thus, employees report better work-life balance, mental and physical health when they feel supported at the workplace.

Comparative Approaches in Analyzing Social Inequalities in Health – Universal Patterns, Cross-Country Differences and Societal Change, Thematic session – Chair: Hanno Hoven - Room K.201

Quality of care, social inequalities in care and access to care: Scoping review's results

Justine Daverio (Geneva University Hospitals, University of Geneva), Delphine Courvoisier (Geneva University Hospitals), Claudine Burton-Jeangros (University of Geneva), Clément Buclin (Geneva University Hospitals), Arnaud Iseli (Geneva University Hospitals)

Background

Health and healthcare have greatly improved over the last decades, particularly in terms of life expectancy. Concomitantly, interest in the quality and equity of care has grown steadily. Quality of care is defined by the World Health Organization as having 7 dimensions: effective, safe, people-centered, timely, fair, integrated, efficient. Quality of care is assessed in many research projects and interventions, and an abundance of academic literature highlights the importance of access to care when addressing the issue of social inequalities in health. Numerous studies have highlighted that unequal access to healthcare can lead to significant disparities in health and clinical outcomes.

Yet, the mechanisms underlying social inequalities in health, which perpetuate the deterioration in access to and quality of care for people with low socio-economic status, remain less clear. The general objective of this literature review is to provide a broad overview of current knowledge on the links between social inequalities in health, access to care and quality of care. It is the first stage of a doctoral thesis.

Method

The three concepts were searched for, in the form of Boolean equations, in the following data sets: Embase, PubMed, Web Of Science (WOS), Worldwide Political Science Abstracts (WPSA), International Bibliography of the Social Sciences (IBSS). As the topic involved the fields of medicine and social sciences, it was decided to choose databases from these two fields. The articles searched for had to be no older than 2012. Inclusion and exclusion criteria included the type of publication, study design, population, comparator, and outcome. Data were collected using Rayyan software, and each article was chosen based on a reading of title and abstract by two independent readers.

Results

A total of 1685 articles were extracted from all databases. After deduplication of same articles in different database, 1158 articles remained. The first screening phase, consulting only the titles and abstracts and done by 5 readers, resulted in the exclusion of 1046 articles and the inclusion of 43 articles. 35 conflicts were observed, resulting in 26 additional inclusions and 9 exclusions. Screening phase 1 therefore resulted in the inclusion of 69 articles. The exclusion criteria were as follows: wrong publication type, patient experience not detailed, wrong population, wrong exposure, wrong study design, wrong comparator, wrong language, wrong outcome. The overriding criteria were wrong publication type and non-detailed patient experience. The articles included were labelled according to the continent in which the research/article took place/focused: Europe, USA, other country. A PRISMA flowchart is currently being produced. Together with the possibilities offered by the extraction form on RedCap, it will be possible to obtain a clear and detailed view of excluded and included items.

The initial results are that there is little research into the mechanisms underlying social inequalities in health, access to care and the quality of care, including an interest in the impact of interactions between individuals (patients and healthcare staff). Overall, research seems to remain at a more macro level, omitting the potential for inequalities that can arise from social interaction, and which can therefore undermine the quality of care. Full results of this scoping review will be presented at the conference.

Conclusion

The results of this scoping review will provide a deeper understanding of the links between the concepts studied. As the first part of a 4-stage doctoral thesis, it will form the basis on which the quantitative and qualitative studies will be built. We are convinced of the potential societal impact that this research project can have by offering an opportunity to adapt existing public health tools and policies in order to improve the quality of care for everyone.

Education and all-cause adult mortality. A global meta-analysis of 603 studies.

Terje Andreas Eikemo (Norwegian University of Science and Technology, Centre for Global Health Inequalities Research), Mirza Balaj (Norwegian University of Science and Technology, Centre for Global Health Inequalities Research), Claire Henson (University of Washington, Institute for Health Metrics and Evaluation), Emmanuela Gakidou (University of Washington, Institute for Health Metrics and Evaluation)

Background

The positive effect of education on reducing all-cause adult mortality is known; however, the relative magnitude of this effect has not been systematically quantified. The aim of our study was to estimate the reduction in all-cause adult mortality associated with each year of schooling at a global level.

Methods

We performed a systematic review and meta-analysis of the effect of education on all-cause adult mortality. We searched PubMed, Web of Science, Scopus, Embase, Global Health (CAB), EconLit, and Sociology Source Ultimate databases from Jan 1, 1980, to May 31, 2023 to identify studies investigating the association between education and all-cause mortality. Two reviewers independently screened titles and abstract, full texts and extracted data. We applied mixed-effects meta-regression models to address heterogeneity in referent and exposure measures

among studies, and to adjust for study-level covariates. The study was registered with PROSPERO (CRD42020183923) and later published in *Lancet Public Health* (doi: 10.1016/S2468-2667(23)00306-7).

Findings

17 094 unique records were identified, 603 of which were eligible for analysis and included data from 70 locations in 59 countries, producing a final dataset of 10 355 observations. Education showed a dose–response relationship with all-cause adult mortality, with an average reduction in mortality risk of 1.9% (95% uncertainty interval 1.8–2.0) per additional year of education. The effect was greater in younger age groups than in older age groups, with an average reduction in mortality risk of 2.9% (2.8–3.0) associated with each additional year of education for adults aged 18–49 years, compared with a 0.8% (0.6–1.0) reduction for adults older than 70 years. We found no differential effect of education on all-cause mortality by sex or Socio-demographic Index level. We identified publication bias ($p < 0.0001$) and identified and reported estimates of between-study heterogeneity.

Conclusion

The comprehensive search strategy in our systematic review, in combination with its global scope, exceeds the scale of previous research on educational attainment and mortality. By including only studies with individual-level data, we reduced the potential for bias from unlinked data, ecological study designs, and country-level average estimates. To our knowledge, this is the first systematic review and meta-analysis to quantify the importance of years of schooling in reducing adult mortality, the benefits of which extend into older age and are substantial across sexes and economic contexts. This work provides compelling evidence of the importance of education in improving life expectancy and supports calls for increased investment in education as a crucial pathway for reducing global inequities in mortality.

Country-differences in work-related mental health during the COVID-19 pandemic: A comparative study with 27,250 employees from 29 European countries

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Introduction

Studies showed that mental health or psychosocial work environments differed by country during the COVID-19 pandemic (Ahrendt et al., 2020; EU-OSHA, 2022). The reasons remain unclear, but macro-level factors such as national occupational safety and health (OSH) regulation or the strictness of public health measures (e.g., workplace closures) may be relevant. Accordingly, we investigate country variations in mental health and their association with indicators of national policies in a study with European data conducted on behalf of the European Agency for Safety and Health at Work (EU-OSHA).

Methods

We analyzed individual-level data from a survey conducted on a representative sample of the employed population in April/May 2022 in 29 European countries (EU-OSHA OSH Pulse Flash Eurobarometer 2022), with information collected via phone from 27,250 individuals (> 16 years). We combined individual-level self-reported mental health and work-related stress with macro-level data (Stringency Index; % of companies with psychosocial risk assessment in the respective country) from different sources (Univ. of Oxford Government Response Tracker; European Survey of Enterprises on New and Emerging Risks). We studied correlations between mental-health indicators and macro indicators. To account for workforce composition and its role in work-related mental health (e.g. higher levels of poor mental health due to a pronounced service sector in a country) the aggregated mental-health indicators are measured in terms of average adjusted predictions that are based on multivariable regressions that were adjusted for sex, age, nationality, employment status, working hours, type of occupations and sector of work.

Results

A little more than a quarter of all respondents (26.8%, weighted) reported poor mental health but this prevalence varied considerably between countries. Results suggest that levels of poor work-related mental health are generally higher in countries with more strict policies ($r\ 0.41$), while being lower in countries with a pronounced risk assessment ($r\ 0.08$). Furthermore, the macro indicators were related to psychosocial working conditions, with positive association between the stringency index and percentage of workers reporting an increase in work stress ($r\ 0.41$)

Conclusion

Even before the pandemic, it was shown that national policies can have an impact on individual psychosocial work environments (Bambra, 2011; Rigó et al., 2022). During the pandemic, these factors may have had an impact on how much change there was in the economy. Our results suggests that workers in countries with a higher emphasis on OSH and with less strict public health interventions had a slightly better overall mental health. The former finding is of particular interest, as it again underscores that it is possible to reduce stress among employees with targeted measures by the employer even in the time of a global health crisis. From this perspective, the consistent implementation of occupational health and safety regulations is an important element in strengthening the psychological resilience of employees regarding possible future crisis events. However, methodologically, it should be noted that this is only a correlative relationship that cannot be interpreted causally. Ultimately, reliable statements about changes over time can only be made on the basis of longitudinal data, where information is available on the individual level at different measurement points in time.

Growing up in digital Europe (Guide) – Why do we need a European birth cohort

Vera Skalicka (Norwegian University of Science)

Background

Recent increases in youth mental health problems in Europe are a major public concern. The COVID-19 pandemic has had a multifaceted and substantial impact on the mental health of children and adolescents, with symptoms of anxiety, depression, loneliness, stress, and tension being widely observed (1). Further, the integration of digital technologies and social media into the daily lives of young people could potentially amplify feelings of anxiety and depression, disrupt sleep patterns, distort body image and foster cyber-bullying (2). The long-term implications of these trends remain unknown and necessitate closely monitoring within and across countries, given the variability in policy responses such as social media regulations and welfare policies across different national contexts. Despite the pressing need, there is currently no comparative data source available to support the wellbeing of children and youth across Europe.

The need for the GUIDE initiative arises from the limitations of current longitudinal studies in individual countries (e.g., the Norwegian Mother, Father, and Child Cohort). These studies are challenging to compare across Europe, due to differences in timing, age groups, questions, and the absence of data on recent generations. While some cross-sectional surveys (e.g., Health Behavior in School-aged Children (HBSC)), offer comparability across countries, they lack the longitudinal design, which is called for to describe predictors of development. This lack of comparative data hinders our ability to compare wellbeing among European child and youth populations over time in varying policy contexts.

Methodology

As a response to this, GUIDE (Growing up in digital Europe) is currently being developed (3). GUIDE is set to be Europe's first comparative birth cohort study of children's and young people's wellbeing. GUIDE aims to track children's wellbeing and psychosocial development along with key contextual factors (homes, neighborhood, childcare and schools) across Europe. A total of 23 countries will provide nationally representative samples designed to maintain statistical power throughout the study's duration. GUIDE will utilize an accelerated cohort design, commencing with a child cohort aged 8 in 2027 and a new-born infant cohort aged 9 months in 2029,

and will follow the participants until age 24. The harmonized design surveying children at regular intervals will establish the first internationally comparable, longitudinal study of European children and young people. GUIDE's methodology and longitudinal design will posit us to conduct robust data analyzes that will advance the understanding of child and youth wellbeing across European states.

Status

GUIDE has been included in the 2021 ESFRI Roadmap. GUIDE will create a balanced life course coverage by providing data on infant, child and youth development to complement and collaborate with two other existing cohort studies - The Generations and Gender Program (GGP) and The Survey of Health, Ageing and Retirement in Europe (SHARE), and a cross-sectional study - The European Social Survey (ESS), all of which collect pan-European adult data. When fully operational, GUIDE will serve as an important source of evidence for developing social policies for children, young people, and families at both national and European levels. We welcome researchers to join the GUIDE consortium and contribute to securing the data collection.

Life Course Perspectives on Health, Thematic session – Chair: Bram Vanhoutte - Room K.202

Long-term consequences on family outcomes of taking paternity leave in the UK Millennium Cohort Study

Anne McMunn (University College London), Baowen Xue (University College London), Yvonne Kelly (University College London), Margaret O'Brien (University College London)

Introduction

Some evidence suggests that fathers who are highly engaged in the first year of life remain more engaged throughout childhood (McMunn *et al.*, 2017). Therefore, policies that encourage paternal engagement may have important implications for persistent gender inequality in unpaid care work and labor market outcomes (Ferrant *et al.*, 2014; McMunn *et al.*, 2019). Yet, the UK is a relative laggard in paternity leave provision at only two weeks paid at £150/week, alongside an unpopular maternity leave transfer scheme (ref on uptake of shared parental leave). Evidence on the long-term impact of paternity leave uptake would support the case for more generous provision. Previous studies using the UK Millennium Cohort Study have shown greater parental involvement in the short-term amongst fathers who take paternity leave (Tanaka & Waldfogel, 2007; Dex & Ward, 2007), but have not tracked whether this increased involvement persists over time. This study investigates whether father's leave-taking around childbirth is associated with their involvement as well as child and parent mental health, and parental relationship quality across children's primary school years. We also investigate whether associations differ by household income.

Methodology

This study uses the Millennium Cohort Study waves 1 (9 months) to 6 (age 14) amongst intact couple families with singleton births at wave 1 and who have available information on father's leave-taking around the time of childbirth (N=12,949). We use multilevel mixed-effects linear (growth curve model) regression for analyzing the association between fathers' leave taking at the time of childbirth and longitudinal trajectories in fathers' engagement (composite z score ages 9 months-11 years), child socioemotional development (Strengths and Difficulties Questionnaire age 3-11 years), maternal and paternal relationship quality (z scores ages 9 months-14 years) and maternal and paternal psychological distress (Kessler score ages 9 months -11 years). We adjust for a range of baseline (child sex; household income; parental education, work hours, NS-SEC occupational class, longstanding illness; maternity leave length and reasons for returning to work; father's number of children outside the household) and time varying (number of children in the household) covariates. Father's employment hours were included as a sensitivity analysis as they are likely to be on the causal pathway. We used interaction terms between paternal leave and household income to investigate differences in associations by income.

Results

Compared to working fathers who took leave around the time of childbirth, working fathers who didn't take leave show consistently lower levels of involvement at all waves, although the association is weaker and attenuated at age 11. This association was stronger in lower income households. Father's leave taking at birth was associated with better relationship quality, but only until the child was 5 for father reports and 7 for mother reports. Father's leave taking at birth was not associated with long-term trajectories in child socioemotional development or parental psychological distress in this study.

Conclusion

Policies which encourage uptake of parental leave for father, and particularly those targeting fathers in low-income households, may have lasting benefits for fathers' engagement through the primary school years.

Health after Mid-Life: The role of adult children's education for older parents' frailty in Europe

Damiano Uccheddu (UCLouvain), Marco Tosi (University of Padua)

Abstract

In ageing societies, intergenerational transmission of (dis-)advantages is a two-way process, since parental investment in children may be reciprocated later in life (Torssander, 2013, 2014). While extensive research has explored the impact of family background on children's life chances, little is known about the importance of children's socioeconomic resources on older parents' health and health inequality – what has been called the effect of “social foreground” on later-life health (De Neve & Kawachi, 2017; Madia, Präg, & Monden, 2022; Potente, Präg, & Monden, 2023).

We use data on parents aged 50 or over living in 29 European countries from the 2004-2020 Survey of Health, Ageing and Retirement in Europe (SHARE) to examine whether adult offspring's educational attainment is associated with parents' Frailty Index (FI). Frailty is conceptualized as a state of vulnerability that reflects an accumulation of deficits in various health domains. The main independent variable is the children's level of education. The educational attainment of each child is reported by the parent at each SHARE wave. This measure is based on the International Standard Classification of Education 1997 (ISCED-97) and refers to the highest level of education attained by the respondent's child.

Preliminary results from random intercept linear regression models, based on a total of 89,752 parents and 210,999 parent-child dyads, indicate that children's higher education is associated with a lower FI, particularly among mothers. We find a positive moderating effect of the educational levels of parents and children, suggesting that a child's higher education tends to compensate for the frailty disadvantage of lower-educated parents (especially mothers). These findings suggest that children's upper intergenerational mobility in the educational ladder reduces health inequalities in later life.

This study provides some preliminary evidence that children's education could influence parents' health across European countries. These findings may have important implications for policy and practice and suggest that efforts to reduce frailty among older adults should also take children's education into account. Consequently, public investments in the education of younger generations produce benefits also for older generations.

In further developing our future analyzes, we plan to examine potential moderating and mediating factors that could influence the links between children's education and parental health, such as the frequency of contact between parents and children, their geographical proximity, and the broader institutional context in which they are embedded. These analyzes will provide a more nuanced understanding of the complex mechanisms linking children's education and parental health, and will inform policy interventions aimed at reducing health inequalities at older ages.

Young adult informal caregivers and mental health: a comparison of depression vulnerability between age groups in Flanders

Jorik Vergauwen (University of Antwerp), Sara De Bruyn (University of Antwerp)

Introduction

Although studies attribute positive consequences to informal caregiving, such as companionship and fulfilment (Cohen, Colantonio et al. 2002, Brown and Brown 2014), it generally comes with a certain cost (Bauer and Sousa-Poza 2015). Caregivers may struggle with reconciling different roles and responsibilities (e.g. caregiving, work and family), affecting life domains such as employment and their social network (Heger and Korfhage 2020, Hajek, Kretzler et al. 2021). For this and other reasons, providing intensive care for family or friends frequently involves the experience of burden, being expressed through a multitude of adverse physical and mental health outcomes (Luichies, Goossensen et al. 2021).

The present study focuses on *young adult caregivers* in Flanders (Belgium), referring to persons between ages 18 and 25 providing informal care, as the role of caregiver warrants particular attention when coinciding with the transition to adulthood (Becker and Becker 2008, Van der Werf, Luttik et al. 2022). The timing of an event in one's life is a key principle of life course studies, implying that the consequences of an experience strongly depend on the life course stage in which it takes place (Elder, Johnson et al. 2003). Building on this tenet, we argue that the occurrence of caregiving may affect individuals differently according to their age. More specifically, a high care burden in young adulthood is expected to exacerbate mental health as it interferes with a developmental period of life path exploration and identity formation. This is also expressed in young adult caregivers' future plans and aspirations, being often bounded to their anticipated care responsibilities later (Hamilton and Adamson 2013). In addition, relative to their older counterparts, young adult caregivers may have less supportive resources (e.g. financial means or a lack of (non-)professional support networks) at their disposal, complicating the outlook on their situation (Stamatopoulos 2018). Hence, our two research hypotheses:

H1: A higher perceived care burden translates into a weaker mental health in young adults (age 18-25).

H2: A higher perceived care burden is more negatively associated with mental health in young adults (age 18-25) compared to older age groups.

Methodology

The analysis draws on data from the Flemish Care Survey (*Zorgenquête*) (Willems, Bracke et al. 2021). The cross-sectional survey project aimed to assess the informal caregiving situation in Flanders (Belgium), targeting a representative sample (7439 respondents) of the Flemish adult population. The oversampling of respondents between 18 and 25 years old allows us to study young adult caregivers in detail.

To test the research hypotheses, the analysis uses the 8-item version of the Center for Epidemiological Studies-Depression (CES-D8) scale from the Flemish Care Survey, being the short version of the regular CES-D instrument to identify mental vulnerability (Radloff 1977), as a dependent variable in ordinary least squares regression. The CES-D8 shows a high scale reliability (alpha is 0.86). The multivariate analysis includes two central independent variables of interest. Age is included as 10-year age groups (except for the 18-25 years old) for a range between 18 and 75 years old. The perceived care burden is computed for respondents who are currently providing or have provided care within the past 12 months. Caregivers are demanded to which extent the care they provide is physically burdensome, is emotionally burdensome, leads to an insufficient amount of time to spend with/for one's family/self, and whether caregivers want more appreciation. Based on these items a scale of the perceived care burden in caregivers (alpha is 0.80) is constructed. Non-caregivers receive a zero score on the burden scale, while the scores of caregivers range between 1 (no burden) and 5 (highest burden). Interaction terms between age group and care burden are introduced to the regression models to examine the association between care burden and CES-D8 scores across age groups. Analysis on measurement invariance across age groups suggests

configural, metric and approaching scalar equivalence for both the CES-D8 and care burden scales. The models include control variables for socio-demographics, household composition, income and health status.

Results

The preliminary results indicate that the 18-25 age group shows significantly higher scores on the CES-D8 scale (y-axis) for different levels of care burden (x-axis) than other age groups. A higher care burden is associated with an increase in CES-D8 score for all age groups, especially for young adults (cf. H1). Furthermore, modeling a linear relationship between age group and care burden yields, on average, steeper inclines for the younger age groups compared to those aged 55+ (and 36-45). The interaction between age group and a categorical variant of care burden suggests that CES-D8 scores are comparable between non-caregivers and caregivers experiencing a low burden in all age groups. The positive association is stronger for higher levels of care burden, in particular for the highest burden in young adults (cf. H2). Hence, this study is the first to demonstrate that highly burdened young adult caregivers are more vulnerable to develop mental health problems as compared to other age groups.

Exploring patterns leading up to syndemic vulnerability: A life-course approach.

Marieke Breed (Leiden University Medical Center)

Introduction

Health is an important (political) topic nowadays. Despite that, the heterogeneity of health outcomes in interaction with people and places needs more exploration. People's life consists of various stages and life events that are intricately intertwined with each other. Acknowledging the dynamic character of people's life's, it is important to pay attention at the accumulation of (dis)advantages over the life course of people.

In the Hague, the Netherlands, single parents disproportionately suffer from cumulation of health and social problems, such as diabetes, depression, headaches, loneliness and low income. It is known that a certain context in combination with events or conditions and their interaction can put people in a more vulnerable situation for poor health problems. We build on the framework of syndemics to gain a better understanding of possible paths to the clustering and adverse interaction of diabetes, depression, headaches among single parents households in the city of The Hague, the Netherlands. The theory of syndemics combines the concentration of two or more health conditions with the notion that the socio-political and environmental context facilitates the health conditions (Singer et al., 2017). By exploring the interaction of multiple health issues and social issues during a life-course we want to gain insight in the clustering in a dynamic context to enhance our understanding of the development of poor health outcomes over time.

Methodology

In this qualitative life-course approach we included single parents (N=15) with at least two health or social issues living in an specific neighborhood in The Hague, The Netherlands. The life-course interview was designed as a semi-structured interview using a life-line to mark critical life-events, including health and social issues. After completing the life-line, we continued with some complementary questions on this critical events to focus more on the interaction of the events, issues and social circumstances. In analyzing the life-course interviews we focused on the interactions and the support of their social network and the system during the life-course that intertwine with the health or social issues of the respondents, looking for patterns to understand the fundamental development of health and social problems over time.

Results

The preliminary results show some patterns in the cumulative disadvantages over time combined with the clustering of health and social issues. We recognize a repeated pattern of adverse events in the early years of the respondents. These childhood adverse events seem to continue to impact respondent's every life in their adult years, for example in suffering from depression and a difficulty with trusting other people. Moreover,

respondents reported adverse events were experienced within and sometimes related to a small (non-supporting) social network in the years after.

In combination with being a single parent, different respondents suffer from depression, sleep problems and loneliness. Moreover, the life-course approach brought to the fore the difficulty of maintaining or building a social network whilst being a single parent. The life-course interviews also enhanced our understanding of how health and ill health is experienced and spoken about. Respondents often did not bring up their health problems in the life-course interviews because of the cumulation of (adverse) life events. When explicitly asking about health problems at the end of the interview, respondents observed that they did not pay much attention to their health problems because of other problems (such as debts, stress about housing).

Conclusion

As a preliminary conclusion, this study shows the strong influence of adverse life events early in life and the (non) involvement of the social network on health and social issues for respondents. While respondents almost never brought up health issues during the interviews, we found that single parents often suffer from a combination of health and social problems such as depression, sleeping problems and loneliness. The life-course approach showed the dynamic interaction between the adverse life events and the (systemic) vulnerability people live in as a fertile ground for multiple health and social issues. Therefore, to enrich our understanding of the fundamental causes of poor health outcomes we need to focus more on the interaction of health and social problems in combination with the contextual and dynamic character across the life-course. It is this combination that eventually gets under the skin.

Studying (Non-)Participation in Health Research : Experiences, Research and Theories, Thematic session – Chair: Carla Ferreira Rodrigues - *Room K.203*

The Sarphati Cohort: A dynamic cohort study in the diverse population of Amsterdam

Luuk Haring (GGD Amsterdam; Sarphati Amsterdam: Research for Healthy Living), Joy Hall (GGD Amsterdam; Sarphati Amsterdam: Research for Healthy Living), Priyanka Sharma (GGD Amsterdam; Sarphati Amsterdam: Research for Healthy Living), Marileen Wieggersma (GGD Amsterdam; Sarphati Amsterdam: Research for Healthy Living), Anton Janssen (GGD Amsterdam; Sarphati Amsterdam: Research for Healthy Living), Marleen Johannes (GGD Amsterdam; Sarphati Amsterdam: Research for Healthy Living), Arnoud Verhoeff (GGD Amsterdam; Sarphati Amsterdam: Research for Healthy Living; University of Amsterdam), Joanne Ujcic-Voortman (GGD Amsterdam; Sarphati Amsterdam: Research for Healthy Living)

Introduction

The Sarphati Cohort is a unique dynamic cohort study of Amsterdam children. The cohort has been set-up to study the development of children from birth until adulthood, with a focus on growth, nutrition, sleep, physical activity and mental well-being. Data collection is linked to routine Youth Health Care consultations, making selected care data on growth and development available for research. Additional data is collected through age-specific research questionnaires. A sub-cohort structure has been implemented to facilitate more extensive data collection in subpopulations, including interviews, observations, and biosamples. The continuous inclusion of new-borns gives this cohort its dynamic character. The success of the cohort largely depends on our ability to involve a sufficiently large and diverse group of participants, including those from different socio-economic groups and multicultural ethnic backgrounds. Therefore, we have developed a multi-channel approach to facilitate inclusive recruitment. The dynamic infrastructure allows us to adapt our recruitment approach over time to target specific groups that are underrepresented.

Methodology

In order to facilitate the inclusion of large numbers of participants, we developed a multi-lingual (web-based) Informed Consent App that registers parental consent. By incorporating an animated video as well as text in

seven languages, we aim to make participant information accessible for parents with various social and cultural backgrounds. The development of the app and the associated content was achieved through several co-creation sessions with Amsterdam parents. Using a mixed method approach with semi-structured interviews and information retention questions, the app was tested in a sample of 30 parents with young children, to study the user experience and to evaluate whether it can be used to adequately inform people and register their consent.

Recruitment started in October 2018. Approaching parents within the youth health care setting has been a main focus of our recruitment strategy, including invitation letters, promotional materials and an on-site face-to-face recruitment approach. Over the past five years we have evaluated and adapted our recruitment strategy and materials. From an initial large focus on face-to-face recruitment up until march 2020 to limited opportunities for recruitment activities during the COVID years. Post-COVID, we expanded our recruitment strategy with an extra focus on underrepresented groups through a neighbourhood-oriented recruitment scheme in which we seek to personally connect with parents outside of the youth health care setting. To support this, we consulted an external design agency to identify what drives underrepresented parents to engage in the Sarphati Cohort. These results should provide direction for the further development of our neighbourhood-oriented recruitment scheme. Other recent activities included social media campaigns and the introduction of a €15 incentive for new parents that sign up and complete the first questionnaire.

Results

Through co-creating and subsequently testing our materials with Amsterdam parents we developed an app that was found to be well-designed, informative and easy to use. Testing the app also led to the identification of some shortcomings of digital informed consents, including trust barriers to the necessary identification procedures and, as with paper consents, individuals who consented without fully familiarizing themselves with all the provided materials. To properly inform potential participants of Amsterdam's diverse population, we therefore cannot rely solely on a digital app. A broader recruitment strategy was drafted where non-digital content such as posters, flyers and brochures and personal contact both on site and remotely in the form of a helpdesk play an important role in supporting the digital consent app.

Since the start of inclusion over 11.000 children enrolled. The Sarphati Cohort has developed into a multicultural ethnic cohort study in which over forty percent of the children have a migration background. In terms of the educational level of parents, the cohort still faces an underrepresentation of vocationally trained parents. Preliminary results of enrolments over the past six months seem to indicate some slight improvements. Results of the design agency suggested to further invest in co-creation with community organizations and organize activities in the neighbourhood to build a "trust" relationship with the parents before attempting to involve them in the Sarphati Cohort.

Conclusion

Setting up the Sarphati Cohort through co-creation with Amsterdam parents proved to be very valuable. It gave us a good sense of what parents expected from a digital consent app, but also showed there were considerable differences in the needs of parents. To facilitate inclusive recruitment, we have therefore invested in a multi-channel approach. The dynamic nature of the cohort, with a continuous influx of new participants, allowed us to adapt our recruitment approach over time. Our continuous efforts to reach a substantially large and diverse sample of participants through co-creation, evaluation and frequent adaptation of our recruitment strategy will help to reach a diverse cohort in the long term. The continued steady growth of our cohort already provides unique opportunities to conduct in-depth research into the health and development of Amsterdam children.

Intersectional dimensions of self-silencing of people with a neuromuscular disease in a clinical trial

Floor Cuijpers (GGZ Geest), Maaïke Muntinga (Amsterdam UMC), Petra Verdonk (Amsterdam UMC), Gonul Dilaver (UMC Utrecht) Mariëtte van den Hoven (Amsterdam UMC), Minne Bakker (Expertisecentrum Beroepsonderwijs)

Introduction

Ethical guidelines protecting medical research participants have been criticized for stripping the sociocultural contexts of research. This critique is urgent considering ongoing calls to account for participant diversity in recruitment and inclusion procedures.

Methodology

Our intersectional analysis of illness narratives explores how sociostructural factors might play a role in participants' exposure to research related harm in clinical trials.

Results

Although widening participation does respond to generalizability concerns, we argue that gendered, classed, and ableist processes of self-silencing could simultaneously enhance risk of harm for participants with multiple oppressed identities.

Conclusion

The call to diversify research populations overlooks how clinical research systems might marginalize participants who occupy (multiple) disadvantaged positions and, by failing to protect them from research related harms. To avoid reinforce the same injustices they aim to counter, researchers should actively involve participants when designing trials.

(Non)-accessing healthcare institutions: What is at stake during negotiations to conduct fieldwork?

Marlyse Debergh (University of Amsterdam), Claudine Burton-Jeangros (University of Geneva), Solène Gouilhers (University of Geneva), Raphaël Hammer (Haute école de Santé Vaud)

Abstract

Based on concrete experiences of different Swiss scholars that we are documenting in a special issue for the journal *SociologieS*, this communication offers a discussion on the (non)-recruitment of participants and the (non)-access of fieldwork in healthcare institutions. Research in healthcare institutions have a rich tradition in sociology. Empirical fieldwork in medical settings helps us to understand many aspects of contemporary societies. However, as this communication shows, access for sociologists to healthcare institutions is far from being granted. Relations between the medical profession and social sciences researchers reveal multiple forms of collaboration in which the autonomy of sociological projects can be undermined or challenged. In a context where ethical concerns and administrative regulation of research data are playing an increasingly important role, this talk addresses the issues surrounding access to healthcare institutions for social scientists. The aim of this communication is to explore current trends revealed by concrete experiences of negotiations, to identify difficulties and obstacles that characterise the new challenges of sociological research. By providing various empirical experiences in healthcare institutions, this communication aims to stimulate sociological interpretation about the current conditions for social sciences research in health and medicine.

5 July: 10:10 – 11:10

Keynote: Andrew Bell – Room K.001

The intersectional MAIHDA approach: What does it do, what can it do, and what is it unable to do?

Dr Andrew Bell's research spans a diverse range of subject areas: his work includes a focus on health inequalities, for example looking at mental health trajectories from a life-course perspective; but he has also contributed to other disciplines including geography, political science, and economics. His work is united by a methodological interest in the development and application of multilevel models, with a focus on age-period-cohort analysis and

fixed and random effects models. He is currently working on an ESRC-funded project developing the use of multilevel models for uncovering intersectional inequalities, particularly in health outcomes.

Before moving to Sheffield, Dr. Bell was a lecturer at the University of Bristol, where he also completed his undergraduate degree (in Geography) and PhD (in Advanced Quantitative Methods). He is currently appointed as Senior Lecturer in Quantitative Social Sciences at the Sheffield Methods Institute.

5 July: 11:30 – 13:00

**Intersectional Perspectives on Family Health, Thematic Session – Chair: Nadine Reibling –
Room K.101**

Parental precarious employment and the mental health of adolescents: A Swedish registry study

Amanda Aronsson (Norwegian University of Science and Technology), Emelie Thern (Karolinska Institute), Signild Kvart (Karolinska Institute), Julio Hernando (Karolinska Institute), Kathryn Badarin (Karolinska Institute); Mireia Julià (Hospital del Mar Nursing School; Hospital del Mar Medical Research Institute; University of Pompeu Fabra), Samira Alfayumi-Zeadna (Li Ka Shing Knowledge Institute), Bertina Kreshpaj (University of Copenhagen), Virginia Gunn (Karolinska Institute; Li Ka Shing Knowledge Institute; Cape Breton University), Theo Bodin (Karolinska Institute), Lluís Mangot-Sala (Karolinska Institute)

Introduction

The adverse effects of Precarious Employment (PE) on workers' health are well-documented, ranging from depression and anxiety to cardiovascular disease and work-related injuries. However, workers' PE can also have implications for other family-members' health, including children. Although this association has been explored to a lesser extent, parental PE can influence the health and wellbeing of children, for instance mediated through low income, job insecurity, straining working hours, high work-pressure, and tensions in work-family balance. Furthermore, compared to fathers, adverse maternal employment conditions associate more strongly with poor health among children, thus indicating the relevance for taking a gendered approach to PE and family health. Given the high prevalence of mental health disorders among adolescents in Sweden, further investigation of parents' employment conditions as a determinant for the mental health of adolescents is warranted. Accordingly, the aim of this paper is to explore the longitudinal effects of parental PE on the mental health of their adolescent children. Moreover, we explore how the association varies depending on whether it is the mother, father, or both, who are precariously employed.

Methods

This register-based study will use the Swedish Work, Illness, and Labor-market Participation (SWIP) cohort. The study population consists of children aged 15 years who lived at home at baseline (2004). Their parents are identified using the Multigeneration Register, and information from the registers will be used to determine the parents' employment arrangement at baseline, which is the main exposure of interest. Based on the Swedish Register-based Operationalization of Precarious Employment (SWE-ROPE), parental employment typologies will be created using latent class analysis (LCA). From the resulting classes, two groups will be selected and categorized as "precarious employment" and "standard employment". The outcome of interest, adolescents' mental health, will be operationalized using in- and outpatient registers. Common mental disorders, suicide attempts and intentional self-harm will be identified through their respective ICD-10 codes. Adolescents will be followed-up from 2005 and until the first incidence of the outcome, the age of 19, death or migration, whichever occurred first. Cox regression models will be used to assess the consequences of parental PE on adolescents' mental health, using standard employment as reference and by controlling for country of birth of parent and child, number of children living at home, the gender of the child, age of parents, the educational level of the parents, parental history of mental disorder, and substance use. Furthermore, results will be stratified by family

formation and parental employment to explore variances in the associations according to the family member who was in PE at baseline (mother, father, both) and to different family formations.

Results

Based on existing theories and empirical evidence, results are expected to reveal that parental PE has some adverse effects on the mental health of their adolescent children. Results are also expected to reveal that the relationship varies according to the gender of the parent in PE, with a stronger association for maternal PE.

Conclusion

Our longitudinal study-design will be an important contribution to a rather large research gap on parental PE and adolescents' mental health. As PE is growing more common in many countries, this study contributes with important insights on the role and reach of insecure and unstable employment may have in terms of mental health within families.

Intersectionality and caregiving: The exclusion experience and coping resources of immigrant women caring for a family member with severe mental illness

Evgeny Knaifel (Ashkelon Academic College)

Introduction

Intersectionality has become a central analytical framework in the study of exclusion and empowerment experiences among women from marginalized communities in various social and health-related contexts (e.g., Azhar & Gunn, 2021; Logie et al., 2011). In recent years, there has been a growing emphasis on employing intersectionality within the domain of informal healthcare research. Most of the studies in healthcare research predominantly focused on family caregivers of individuals with dementia (Hangelaar et al., 2023; Liu et al., 2022) and demonstrated how social categories, such as age, gender, socioeconomic status, and ethnicity, interact with each other and influence caregivers' well-being and health.

Despite the association of mental healthcare with various forms of stigma and discrimination directed at individuals with severe mental illness (SMI) and their families (Martin et al., 2017; Pescosolido et al., 2021), intersectionality as a critical analytical concept is rarely used in this field (Hangelaar et al., 2023). The use of intersectionality is particularly crucial in the case of immigrant caregivers who need to cope with culture and immigration-related stress in addition to their burdens and responsibilities as mental health caregivers (Knaifel, 2022; Kung, 2016).

The current study attempts to fill this gap by examining the experiences of immigrant women from former Soviet Union (FSU) in Israel caring for a family member with SMI (such as schizophrenia or mood disorders). Accordingly, the research questions are: 1) What are the various intersecting social categories in the lives of female immigrant caregivers?; 2) How do immigrant women caring for a family member with SMI experience intersectional stigma and exclusion?; and 3) How do immigrant women caring for a family member with SMI cope with their social and health-related adversities?

Methodology

Qualitative research aligns well with intersectionality, as it allows for the exploration of the complex interplay of multiple identities and disadvantages through in-depth, descriptive narratives of individuals' lived experiences (Christensen & Jensen, 2012). Semi-structured in-depth interviews were conducted with female immigrant caregivers from the FSU in Israel. The inclusion criteria were: (1) serving as a caregiver for a family member with SMI who is recognized by the National Insurance Institute of Israel as psychiatrically disabled; (2) being an FSU immigrant who immigrated to Israel after 1990. A total of 26 women participated in the study, who were recruited using purposive and snowball sampling methods. The data analysis utilized a qualitative content approach, which involves both inductive and deductive processes. Inductive analyzes were used to identify codes

and categories that emerged from the data, while deductive approaches were applied to explore categories guided by the intersectional theoretical framework informing this analysis.

Results

The findings revealed that the participants experienced stigma and exclusion in several intersecting categories: 1) socio-economic status – as middle-aged immigrants; 2) ethnicity - as Russian-speaking women in Israel; 3) gender – as victims of domestic violence; and 4) mental health stigma - as mothers of adults with SMI suffering from family stigma. The intersection of these excluded identities has negative implications for women self-perception, their sense of social belonging, and their access to essential healthcare resources for personal and family recovery processes.

Alongside with multiple exclusion experience, the findings also revealed the resources that helped participants to cope with their hardships: 1) spirituality and religious faith; 2) support groups in family centers; and 3) social activism. The reduction in existing social resources have prompted these women to acquire new coping resources that diminish their sense of loneliness and enable them to develop a sense of belonging to new communities. These experiences attest to the resilience and empowerment these women have developed in light of, and perhaps because of, the intersectionality of their marginal positions.

Conclusion

This is the first study to examine the experiences and coping resources of FSU immigrant women in Israel caring for a family member with SMI through the lens of intersectionality theory. The findings demonstrate how multiple intersecting dimensions, such as immigrant status, ethnicity, gender, and mental health stigma, interact with each other and influence caregivers' experiences and coping.

The main implication of the study is that traditional concepts in informal healthcare, such as burdens and rewards of caregiving (Shiraishi & Reilly, 2019), can be investigated from the intersectionality perspective. This is especially crucial for disadvantaged groups, such as immigrants and ethnic minorities, who suffer from multiple social adversities that go beyond the scope of standard situations of caregiving for a family member with SMI. Professionals in social and healthcare services must recognize the contextual characteristics of female immigrant caregivers, minimize intersectional stigma, and assist them with accessing valuable resources.

The main study limitation is that it has conducted in the very specific cultural context - FSU immigrants in Israel. Future studies should compare the experiences of female caregivers from different cultural and geographical regions for a better understanding of the universal and contextual mechanisms of intersectionality in informal healthcare research.

Mothers' perceptions of the relationships between their wellbeing and their parenting identities, practices and beliefs

Hillary Collins (University of Glasgow), Shona Hilton (University of Glasgow), Daniel Wight (University of Glasgow)

Introduction

Previous epidemiological research has found associations between various social factors and maternal wellbeing, including maternal age, social support, education level and having a child with conditions affecting their behavior (e.g. Bayrampour et al., 2015; Martini et al., 2015; Benson, 2016; Chung et al., 2004; Spinelli et al., 2013; Lee, 2013). There has been empirical study of endorsement of aspects of the parenting ideology 'intensive mothering' (Liss et al, 2012) and further research examining the association between such varying endorsement and maternal wellbeing (Rizzo et al, 2013). Intensive mothering is a set of parenting behaviors and beliefs observed by Sharon Hays to be considered to be appropriate ways to raise children in a middle class, American context (Hays, 1996), and has been applied and observed in other Anglophone contexts (Faircloth, 2014). A related belief around parenting, parental determinism, coined by Frank Furedi, is the association between quotidian parenting

behaviors and their children's, and society's, futures (Lee, 2014). Furedi (2008) and others (eg Lee et al, 2014) have argued that intense policy and social interest in parenting, related to such deterministic thinking, may feel pressuring and indeed induce a state of paranoia in parents. Joan Wolf (2013), in discussing the social implications of breastfeeding rhetoric, used the term 'total motherhood' to describe an ideology where any possible risk to a child should be mitigated no matter what the cost, or sacrifice, to the mother.

This paper presents research which examined mothers' perceptions of how their parenting beliefs and practices, particularly those aligned to Hays, Furedi and Wolf's conceptualizations, impact their wellbeing.

Methodology

Semi structured interviews were carried out with 23 mothers in Scotland (living in areas across a spectrum of deprivation and affluence, 14 with university degrees, 16 white Scottish, 3 South Asian (born outside Scotland)). Interview transcripts were analyzed thematically using an amended version of the method described by Braun and Clarke (2006). This analysis was additionally structured using framework analysis. Results are presented using five domains of holistic wellbeing.

Results

The Office of National Statistics (2019) set out five domains of wellbeing, which in this paper are used to examine descriptions by mothers of impacts to their wellbeing of various aspects of their parenting lives.

- *Domain 1: Personal Well-being.* Mothers gave nuanced accounts of the relationship between motherhood and their feelings of satisfaction with their lives. Some mothers talked of feelings of vulnerability related to motherhood and there was discussion of liking their children, which may offer opportunity for pay off of negative aspects of motherhood. There were accounts of feeling guilty for not behaving in child-centered ways, which is a key aspect of the ethic of intensive mothering. There were also several references to worry or fear that their actions or inaction could cause harm to their children, a line of thinking that could be perceived as aligned to notions of parental determinism.
- *Domain 2: Our Relationships.* There was discussion of parenting beliefs and practices causing tensions with their partners and feelings of distance from some friendships. There was mention of a relationship between new motherhood and loneliness. However, some found new motherhood offered new social opportunities. Some described feeling judged due to their behaviors or beliefs related to infant feeding or discipline.
- *Domain 3: Health.* Childbirth, breastfeeding and accidental injury brought some mothers physical pain and there was mention from four mothers about the impact of motherhood on their mental health.
- *Domain 4: What we do.* Several mothers described reduced autonomy since becoming a mother and many had either temporarily or permanently altered their employment arrangements in the perinatal period. There was consensus that having young children negatively affected mothers' sleep and an articulation of how such a lack of sleep reduced overall wellbeing.
- *Domain 5: Personal Finance.* The financial outlay described by mothers as involved in undertaking parenting activities perhaps indicates implicit endorsing of an element of the intensive mothering ethic—that appropriate parenting behaviors are financially expensive. The accounts from some mothers of dealing with this expense hinted at notions of total motherhood.

The use of framework analysis highlighted some potential relationships between mothers' intersecting demographic factors, for example social class and immigration experiences, and their descriptions of engagement with different parenting ideologies, and in some cases, their wellbeing.

Conclusion

Mothers reported various aspects of their mothering identities, beliefs and practices impacting perceptions of their wellbeing aligned right across different domains of holistic wellbeing. These impacts were at times both

positive and negative, with much nuance expressed. There is suggestion of considerations of balance between sacrifice and pay-off in mothers' accounts.

This research is contextualized by epidemiological public health research and parenting culture studies literature and thus presents a relatively novel focus by offering a sociological perspective on maternal wellbeing and an empirical examination of some theoretical concepts.

Cross sectoral support for expectant and new parents in vulnerable positions – A realist evaluation

Louise Thomsen (University of Southern Denmark), Clara Andersen (University of Southern Denmark), Marianne Frederiksen (University of Southern Denmark), Charlotte Overgaard (University of Southern Denmark)

Introduction

Women in pregnancy, living with psychosocial vulnerability are at increased risk of perinatal and maternal mortality and morbidity (Jones et al., 2022). Psychosocial vulnerability covers a wide range and combinations of factors that positions the woman and her infant at risk during pregnancy, birth and postpartum including demographic factors such as belonging to an ethnic minority group, being under the age of 20, having low socio-economic status, residing in a deprived neighborhood, and being a woman (Jones et al., 2022; Sule et al., 2022). Prior mental health problems, lack of social support, experiences of domestic violence and experiences of loss, trauma, or abuse also positions women in pregnancy vulnerable to adverse pregnancy and birth outcomes (Scheele et al., 2020). Early identification of vulnerability and interprofessional support is recommended by health authorities and have proved beneficial for the health and wellbeing of parents in vulnerable positions, their birth outcomes and their child's health and wellbeing (D'haenens et al., 2020). However, Studies show that pregnant women in vulnerable positions may have mixed or negative experiences of psychosocial risk assessment and support, and in some cases find that health care professionals act dismissive, disrespectful, or judgmental (Downe et al., 2009; Frederiksen et al., 2021). Identifying vulnerability as a professional relational practice is a balance between an expert perspective and the lay perspective (Spiers, 2000) and thus a balance between power and care (Klode et al., 2020).

This study explored relevant contexts, mechanisms and experienced effects, in the perspective of parents, of a cross sectoral intervention for expectant and new parents in vulnerable positions in a Danish region. A dialogue-based vulnerability assessment is offered to all women and their partners in pregnancy during their first midwife consultation, with the aim to identify and subsequently offer support to women and their partners in vulnerable positions. We undertook a realist evaluation to contribute to the theory base of this and similar interventions.

Methodology

The study is part of a qualitative realist evaluation (Pawson & Tilley, 1997) of the cross sectoral intervention to explore how, for whom and under what circumstances the intervention works. 25 realist interviews (Manzano, 2016) were conducted, involving new parents receiving support across the region to refine an initial program theory of the intervention developed by the research team based on document analysis, interviews and workshops with key professional stakeholders delivering the intervention (Ellehave et al., 2023).

Results

Parents in different vulnerability positions express that they benefit from uncovering their vulnerabilities and need for support in a safe and compassionate space during the assessment with their midwife. The professional approach must be compassionate, accepting, and emphasizing resources, normality of the pregnancy as well as vulnerabilities. Uncovering vulnerability is experienced as supportive or leading to parents feeling judged depending on professionals' approach, and services offered. Parents with a history of mental illness or social disadvantage are well prepared or on their guards when entering the intervention because of their previous experiences with the health and social systems. Having enough time for the dialogue-based assessment and having professional experience or confidence are key context stimulating a compassionate approach.

Early bridging by the known midwife to other services and thus continuity in care increases parents' feeling of safety before and after birth if the approach is compassionate and interprofessional relations are well founded in good collaborative practice promoting informational, management and relational continuity (Reid et al., 2002; WHO, 2018). Gaps between services can lead to discontinuation of the safe space and experiences of stigma, control and uncompassionate treatment. Some parents experienced that the focus of support shifted from their wellbeing to solely the baby's wellbeing after birth leaving parents to reach out for support on their own. Parents benefit from group-based services by meeting likeminded parents in the context of known health and mental health professionals.

Conclusion

A compassionate professional approach along with continuity is central for parents in vulnerable positions to build trust and to engage in support. The intervention varies across the region due to different implementation practices, resources, and service histories. Integrated cross sectoral and cross service collaborative practices, continuous support of the parents after birth and availability of targeted group-based services where parents can meet and socialize is recommended.

Ageing and Health, Regular Session – Chair: Francesco Miele – Room K.102

Becoming a Grandparent and its Impact on Morbidity in Adults aged 40-68: Applying Principles of a Target Trial on a National Cohort Study

Can Liu (Stockholm University), Josephine Jackisch (University of Fribourg)

Background

The demographic change of increasing life expectancy has led to large increases in the average shared lifetimes between grandchildren and grandparents. For instance, a grandmother born in 1900 in Finland had about 17 shared years with at least one grandchild, while the shared years increased to almost 27 for grandparents born around 1950 (Chapman et al., 2017; Song & Mare, 2019). With grandparents, in general, living longer and healthier lives, their involvement in caring for their grandchildren has also increased. For instance, in Sweden, more than half of grandparents are involved in caring for a grandchild (Zanasi et al., 2023).

Grandparental involvement may benefit grandchildren's outcomes, but whether its benefits grandparents' health remains somewhat controversial. Some of the previous studies showed positive associations between grandparental care and subjective health (Danielsbacka et al., 2019; Di Gessa et al., 2016), mental health (Arpino & Bordone, 2014; Tsai et al., 2013), as well as physical functioning (Danielsbacka et al., 2019). Evidence also documents decreased mortality among grandparents (Christiansen, 2014; Hilbrand et al., 2017). In contrast, being a grandparent might not always be positive. Both overburdening care responsibilities and negative emotions can lead to adverse health outcomes. An established body of literature documents adverse health effects for custodial grandparents that are the primary caregivers for grandchildren (Hayslip & Kaminski, 2005; Kelley et al., 2021). Moreover, it has been noted that being a grandparent and not being in contact with grandchildren might lead to negative emotions (Drew & Silverstein, 2007).

The uncertainty of the impact is partly because of the many difficulties in using observational data to infer the causal effect. If we ask a causal question of whether becoming a grandparent positively or negatively impacts hospitalization risks, we might encounter problems due to selection and immortal time bias. A randomized design can help to reduce such bias; however, such a randomized study would not be realistic or ethical. Therefore, we propose applying an emulated trial framework to minimize bias when estimating the effect of becoming a grandparent on cause-specific hospitalization risk using observational data.

Objectives

This study aims to assess the effect of becoming a grandparent (for the first time) on ICD-10 chapter-specific hospitalization risks.

Methods

We use a target trial framework to minimize selection and immortal time bias and leverage comprehensive data of a birth cohort built on the entire population born in 1953 and residing in Sweden in 1963. Cohort members are linked across generations. We will design and conduct 24 hypothetical yearly trials (1993-2016) comparing cause-specific hospitalizations of those who had their first biological grandchildren born in the trial-starting year to those who remain nongrandparents. All hospitalizations are retrieved from The Patient Register and observed from entering each trial until emigration, death, or end of 2019. Demographic, socioeconomic, and health indicators are measured yearly for each cohort member. We will use pooled logistic regression models to estimate the causal effects of the birth of a first grandchild on cause-specific hospitalization, adjusting for baseline and time-varying confounders and censoring using inverse probability weighting.

Preliminary Results

Hazard ratio and standardized risk curves of hospitalizations for grandparents compared to nongrandparents will be reported.

Conclusions

The anticipated result will contribute to understanding the link between grandparenthood and health.

Inequalities and discriminations against older persons: An Italian study on ageism in healthcare services (PNRR Age-It)

Elena Allegri (University of Eastern Piedmont), Cristina Calvi (University of Eastern Piedmont), Eugenia Mercuri (University of Eastern Piedmont)

Introduction

The contribution presents some preliminary results of a research investigating the presence of ageism in some healthcare services dedicated to older persons - excluding long-term care (LTC) services. The literature on the topic suggests that ageism in healthcare contexts is present at several levels: in social interactions, organizational cultures and health policies (Levy, 2016). Ageist behavior and attitudes in the context of healthcare not only can contribute to social exclusion in old age (Walsh et al. 2017), but they can have dangerous implications for the health of patients as well, further exacerbating existing conditions of inequalities among older adults.

The existence of stereotypes and discrimination in healthcare practices is an existing element in the literature of reference: in particular, on the one hand, stereotypes have emerged related to symptoms being considered “normal” in older age groups (Iliffe et al. 2005; Makris et al. 2015) and the possibility of a widespread belief among healthcare personnel about high non-response to treatment due to age (Skirbekk and Nortvedt 2014); on the other hand, discrimination against older adults has been found during the diagnosis phase (Rudd et al. 2007), but also during the treatment and disease management phase (MacRae 2018), as well as in access to research and clinical trials (Cruz-Jentoft et al. 2013). Studies that have considered implicit ageism have pointed to the presence of dangerous manifestations such as the belief that older patients tolerate treatment less than younger patients (Skirbekk and Nortvedt 2014), while research that has investigated self-directed ageism has pointed to the presence of more manifestations in older patients, such as the refusal of certain diagnostic procedures or examinations and/or certain treatments (Wyman, Shiovitz-Ezra, Bengel 2018). If ageist practices also influence clinical decision-making, the patient behavior conveyed by self-directed ageism may also have an impact on healthcare processes and outcomes. To date and to our knowledge, yet, no research has been conducted on ageism in health care settings in the Italian context: this contribution aims at beginning to fill this gap.

Methods

The part of the research presented here, conducted in northern Italy with healthcare workers (doctors and nurses) explores the ageist practices that can take shape in professional contexts of care and cure through the reconstruction of certain representations and definitions that guide the actions of doctors and nurses and that can favor ageist practices. The aim of this first, exploratory phase is to recognize common conceptual categories at the basis of cure and care work with older adults, in order to better investigate the micro-level practices of healthcare workers. The research adopts qualitative methods: in this phase, two focus groups have been conducted – one with doctors and one with nurses – to reconstruct, on the one hand, the meanings that professionals attribute to the concepts of ageing and self-sufficiency/non-self-sufficiency; on the other hand, the possible ageist practices enacted in the professions and in the organizations in which they work. Based on the results of the focus group, the interview outline will be addressed to approximately 100 professionals (doctors, nurses and social workers and managers of health and social services), and will be reported on during the conference.

Findings

The analysis sheds light on the coexistence of two mechanisms that can potentially generate ageist practices in healthcare professions: the first acts at the micro (individual) level through stereotypes and prejudices that can condition relationships with older patients; the second is at the meso level and acts through the organizational constraints within which professionals work.

Conclusions

The results of this work will be useful for improving healthcare services for the older people, also considering the fact that the elderly constitute the largest group of users of care services and generally the most expensive for healthcare (Levy et al. 2020). For this reason, it appears increasingly necessary to redefine healthcare for old persons in anti-ageist terms (Coupland and Coupland 1994), i.e. with an individualized and person-centered approach to care (Breslau et al. 2016) and this research also helps in this direction. In subsequent phases of the research, ageist and potentially discriminatory practices in micro-level interaction between healthcare (and socialcare) professionals will be further explored.

Guardian, Oracle or Replicant? Metaphors on AI and age-related chronic conditions in scientific literature.

Francesco Miele (University of Trieste), Veronica Moretti (University of Bologna) and Ludovica Rubini (University of Trieste)

Abstract

Our contribution aims to present the main findings of an in-depth literature review on the use of AI in chronic conditions. With the recent renaissance of AI, policymakers, academics, and practitioners have increasingly focused on the promises and challenges of intelligent machines in managing chronic conditions. Particularly, attention has been directed towards chronic diseases associated with aging processes (such as Parkinson's, dementia, certain types of cancer, and diabetes mellitus), given the increasing ageing population processes and its potential impact on national healthcare systems.

We conducted a literature review using the meta-narrative review methodology to map the storylines emerging in scientific literature. We screened 96 scientific papers, combining the PubMed database with research from leading social science journals in health research (such as Social Science and Medicine, Sociology of Health and Illness, Science Technology and Human Values, Health Sociology Review, Qualitative Health Research), resulting in a final sample of 18 articles. We deliberately focused on mixed-method or qualitative studies, excluding clinical literature, and exclusively considering contributions with a social science background.

The final sample was analyzed to identify emerging narratives, which we synthesized using metaphors to highlight the hopes and concerns that scientific literature attributes to AI in healthcare. A first group of contributions conceptualized AI as an 'artificial guardian', suggesting that intelligent technologies could fundamentally monitor the health status of people with chronic conditions. A second group emphasized the predictive capabilities of AI, metaphorically depicted as an 'oracle', envisioning intelligent machines in this role. Lastly, a third group focused on how AI could potentially replace healthcare professionals in supporting people with chronic conditions, for which we adopted the metaphor of a 'replicant', encapsulating both positive and negative expectations about a future with widespread use of AI in healthcare.

For each metaphor, we explored the roles associated with AI and the ethical, political, and organizational tensions highlighted in the literature regarding the integration of intelligent technologies across different healthcare domains. The final part of the presentation will address gaps in the current debate on AI and age-related chronic conditions, suggesting future research directions.

Social capital and all-cause mortality before and during the COVID-19 pandemic among people aged 50+.

Katarzyna Zawisza (Jagiellonian University Medical College), Paulina Sekula (Jagiellonian University Medical College), Michalina Gajdzica (Jagiellonian University Medical College), Beata Tobiasz-Adamczyk (Jagiellonian University Medical College)

Introduction

Prior to the pandemic, studies demonstrated the mainly protective role of structural social capital on all-cause mortality, less evidence had been found for a protective role for cognitive social capital. However, some findings from the early stage of the pandemic suggest that civic participation and group affiliation may be associated with more COVID-19-related deaths, as was interpersonal trust. This suggests that social capital is a double-edged sword, having diverse effects on health outcomes, both positive and negative. Thus, the study aimed to verify indicators of individual social capital as risk factors for 7.6-year all-cause mortality before COVID-19 pandemic and 1.6-year all-cause mortality during of the pandemic among men and women aged 50+ years in Poland.

Methodology

The results are based on prospective cohort study. The Polish part of the COURAGE in Europe cross-sectional baseline study was conducted in 2011. The analysis included 2913 face-to-face interviews with randomly selected community-dwelling individuals. Information about deaths was obtained from the State Systems Department on Oct 7, 2021. Various aspects of structural and cognitive social capital were measured. The Cox proportional hazard models were used. Survival analysis was performed separately at two time intervals: before and during the pandemic. For each indicator of social capital five models were estimated: 1 - unadjusted, 2 – adjusted for age, place of residence, marital status, SES, 3 – additionally adjusted for smoking, drinking alcohol, BMI and physical activity, 4 – additionally adjusted for self-rated health, total number of diseases, WHODAS 2.0 and grip strength, 5 – additionally adjusted for depression and loneliness.

Results

The comparison of these who died during the follow-up and alive people showed that men and women who died during the follow-up were older, less frequently married, with lower SES as well as with worse functional and health status than the group of alive people. Comparison of the group of people who died before the pandemic and during that time showed that both men and women from the latter group were younger and had higher SES. Women and men who died after the onset of the pandemic were more likely to be physically active, in better health and functional status, than those who died before the onset of it.

The results of the cox regression analysis indicated that before the pandemic, a protective effect of structural (formal and informal social participation) and cognitive social capital (trust in family, trust in co-workers) on the

risk of death was observed in women. However, a negative effect of cognitive social capital (trust in strangers) was found for women and men. No positive effect of social capital during the pandemic after controlling for the health-related characteristics was found. A negative effect of generalized trust on all-cause mortality during the pandemic was discerned for men, a negative effect of the level of one's social network was found in women.

Conclusion

Our study has shown that resources obtained during relatively stable periods in terms of formal and informal social participation or trust in co-workers and trust in families resulted in lower all-cause mortality before the onset of the pandemic, but they lost their importance during this extraordinary period. The observed patterns of relationships were totally different for analyzed periods of time, and different for men and women. Consequently, planning of social interventions directed towards middle and older age groups should consider various actions for men and women separately. The need for continuous evaluation of implemented social interventions was emphasized.

Pandemics and Health, Regular Session – Chair: Sarah Van de Velde – Room K.103

Navigating ‘Uncertainty Boost’: Media analysis of vaccination debates before and during the COVID-19 pandemic

Eva Soares Moura (Charles University), Dino Numerato (Charles University)

Introduction

The global pandemic of COVID-19 has amplified uncertainties related to health, well-being, and socio-economic aspects of life in general (e.g., Douglas et al., 2020), and exacerbated the existing uncertainties surrounding vaccination in particular (e.g., Dubé et al., 2015; Kricorian et al. 2022; Sagy et al., 2018). Scientific, political, and public debates on various aspects of vaccination, including its efficacy, safety, or necessity, have intensified, with conflicting perspectives becoming more pronounced and present within uncertainty management. The extensive media coverage of the pandemic inevitably contributed to the ways in which uncertainty was experienced and managed (Nagler et al., 2020). Previous research on media communication, and management of uncertainty suggests that journalists can handle uncertainty through excluding information, juxtaposing conflicting messages, or addressing the issue through the structure or language, using diverse framings (e.g., Capurro et al., 2021; Holland et al., 2012; Lehmkuhl and Peters, 2016; Rooke, 2021). Within the context of the COVID-19 pandemic, news media have been criticized for not openly discussing mainly the scientific uncertainties related to COVID-19 (e.g., Fleerackers et al., 2021; Martin et al., 2020). Against this backdrop, we pose the following question: how uncertainties and risks changed over time in media discourse? While current research extensively theorizes the concept of uncertainty during the COVID-19 pandemic (e.g., Brown, 2020; Paek and Hove, 2020), uncertainty was viewed as stable and immutable in time. With our contribution, we view uncertainty as situated, context-dependent, dynamic and open to changes, depending on the temporality of the COVID-19 pandemic as well as the longer history of pre-COVID-19 debates concerning vaccination.

Methodology

Media content analysis was conducted on a corpus of articles collected from three Czech online media (zpravy.iDNES.cz, Aktuálně.cz, and Novinky.cz.) that encompass the heterogeneity of the Czech media landscape. More specifically, we focused on the period from April 1, 2019 to 31 December 2021, using March 11, 2020 as the date dividing the pre-Covid and Covid periods. Three keywords, including synonyms for vaccine and/or vaccination ("očkov", "vakcin", and "vakcín"), were used to identify articles for this qualitative content analysis, with a subset sampled and categorized into pre-Covid (175 articles) and Covid (680 articles) datasets.

Results

The preliminary analysis reveals that the media dealt differently with risks and uncertainties as the pandemic progressed. Their initial tendency was to avoid uncertainties surrounding the pandemic and vaccination by

presenting a more optimistic perspective and hopes, with only little acknowledgement of the unknown aspects of the health crises. This was done mainly through references to political authorities. As the pandemic progressed, the media that initially portrayed uncertainties as manageable, started to accept uncertainty as a part of expert knowledge. More precisely, initially, media outlets concentrated on disseminating clear, evidence-based information to alleviate uncertainty among the public regarding vaccine safety and efficacy. However, as the pandemic advanced, skepticism emerged regarding COVID-19 vaccination side effects, leading the media to cautiously acknowledge and discuss them, although selectively and situating the risks within controllable boundaries. Moreover, the media progressively started to report on different types of until then undiscussed uncertainties, including economic or social. As such, next to the pandemic-related terms like "uncertainty event" or uncertainty as a "master frame" in news coverage, we introduce the term "uncertainty boost" which refers to the multiplication of uncertainties, where a new spectrum of uncertainties emerges and may increase during the resolution process. This happened in relation to various topics that introduced these new uncertainties, encompassing vaccine efficacy and safety, types of vaccines, and shifts in recommendations and evidence. Thus, our preliminary findings suggest that uncertainties are multilayered and located in different areas, spanning health, economic, scientific, and social domains. They form a complex web, where one type of uncertainty cannot be separated from another, rather creating a complex network of uncertainties.

Conclusion

Our analysis reveals distinct patterns in how media reported on uncertainties over the analyzed period, from initially concealing and marginalizing uncertainties to partially acknowledging them. We also expect to identify nuances and differences across the media analyzed. However, in relation to certain issues and aspects of vaccination, such as side effects, the media only partially acknowledged the risks and uncertainties. This might also be the result of the emergence of new uncertainties over time that gain more attention in media coverage, pushing the previous ones aside or existing alongside them as "manageable". We contribute to the current debates by introducing the term "uncertainty boost," which highlights the growing complexity and multiplication of uncertainties over time.

The neglect of early anti-COVID-19 therapies: The conflict between practice-based and evidence-based medicines

Giampietro Gobo (University of Milan), Enrico Campo (University of Milan), Barbara Sena (University of Bergamo)

Introduction

Since February 2020, strategies aimed at containing and managing the Covid-19 outbreak have been developed by the governments of European countries. Among these measures, the possibility of an early treatment of the disease has been considered of fundamental importance, both for curing the disease and governing the outbreak. Despite their potential, early (practice-based) therapies were neglected in Italy and the debate around them gave rise to a strong conflict between their proponents and opponents, to the point that some of the former (mainly General Practitioners) organized a properly political movement in order to promote the integration of early home therapies in the official health protocols.

Unlike, opponents (mainly scientists) argued the necessity of waiting for the outcome of the randomized (evidence-based) studies; which, however, would only arrive after several months. Hence, a harsh conflict developed between several GPs (supporters of the practice-based approach) and many scientists, much sustained by the most of the mainstream media.

Methodology

We conducted an empirical research on two sets of data: articles published by Italian media and 16 discursive interviews with experts. With the double aim of obtaining a map of the coverage of the topic and selecting the potential interviewees, we conducted a preliminary inspection of several national newspapers and news sites. Within those sources, we collected all the documents (statements, interviews, articles, comments) relevant to

the topic that were published from February 2020 to February 2022. Moreover, we were systematically engaged in integrating or deepening the information presented in the articles with more specific research on webpages of political and health authorities (WHO, Ministry of Health, Italian regions), pharmacovigilance agencies (AIFA, EMA, FDA) or scientific journals. At the end of the collection process, we had gathered 237 articles.

Through this preliminary inquire, we were able to identify about 42 experts (and potential interviewees) among those who expressed favorably about early home therapies. Within this group, we further selected 16 of them according to six variables: geographic area of practice (north/center/south), professional qualification (general practitioner/health care manager/hospitalist), involvement in scientific research (no/occasionally/full-time), gender (man/woman), orientation toward vaccines (very favorable/favorable/unfavorable/very unfavorable), and affiliation to movements or associations promoting early home therapies.

Results

The paper highlights this conflict between different visions of medicine and science, the hierarchy of scientific knowledge and professional skills, the downgrading of GPs' practical knowledge and experience, the multiple meanings of the concept of 'empirical evidence'. As consequence, GPs' therapeutic proposals were excluded from the public health services, not recognizing and valuing the diverse perspectives and needs of patients and healthcare providers. In addition, the paper consider health protocols as socio-technical objects embedded in a vast range of cultural, political and economic factors that contributed to the general resistance towards those treatments and the exclusion of home therapies into 2020 national guidelines.

However, in 2022, although promoters of early therapies were often opposed and marginalized, their essential message was eventually accepted. Far from being restricted to the administration of some specific drug, the logic of early home therapies consisted in the need to start treatment as early as possible, especially in subjects at risk, and in regulating the inflammatory response once the patient enters the more severe stages of the disease; with the ultimate goal of reducing hospitalizations as much as possible. It is precisely this "legacy" what survived the debates over specific drugs and got to be recognized by top scientists (Perico, Cortinovis, Suter and Remuzzi 2022), institutions and media. Proof of that, the last version of the ministerial protocol for home treatment of Covid-19 patients and the last guidelines published by AIFA actually recommend the administration of antiviral treatments in the first days after the onset of symptoms, as the use of immune-modulating therapies in later stages. Now that the issue seems to have lost its divisive character, early home therapies are considered an important strategy to govern the syndemic, to the extent that they can be considered capable of reducing the pressure on hospitals by 85-90% (Cuppini 2022). However, in the conflict, the GPs succumbed and many patients did not have treatment (i.e. they died) until the beginning of 2021, when the anti-Covid vaccines arrived.

Conclusion

What the debate on home care in Italy clearly shows, in the end, is the need to strengthen territorial medicine and rethink its relationship with the other levels of the health system – necessities that cannot but be implemented through proper *political* decisions aimed at increasing investments in this regard. Since the announcement of their activation, the Next Generation EU funds have been regarded as a major opportunity for Italy to take the first steps toward this direction. Yet, the recent downsizing of the Care Support Units, "the more precious legacy of the whole pandemic" (Interviewee n. 6), seems to point exactly to the opposite one.

Neoliberalism, Illiberalism and Pandemic Management Tools: Inequalities between European countries in Excess COVID-19 mortality

Katalin Kovács (Hungarian Demographic Research Institute)

Background

The COVID-19 pandemic has had a profound but disproportionate impact on countries worldwide. Some countries experienced tragically high levels of mortality. This raises the question of whether this outcome was

the result of simple inappropriate use of the classic and new pandemic management tools or other factors such as health status, wealth or political orientation. To shed light on this issue, our study examines the possible drivers of excess mortality due to COVID-19, such as intensity of pandemic management interventions and other country level characteristics across European countries.

Objectives

Numerous political studies demonstrated, that political orientation, not in the form of the presence of any political leader with particular orientation, but in the form of practices regarding welfare and democratic governance has an impact on pandemic outcome. So that we formulated our research question around the role of neo-liberalism and illiberalism, to explore if they alone, or via the application of certain pandemic management tools determined the mortality outcome of the pandemic.

Methods

Our basic assumption was, that this question is worth to examine by separating the particular waves of the pandemic, because some pandemic management tools, most notably, vaccines, were not available during all of the waves, and knowledge, experience, perceptions and expectations were all different during the consecutive pandemic waves.

The inclusion of countries into this study also corresponded to the features of pandemics such as appearing in waves. We assumed, that comparability is best, if countries experience the more or less same sequence of events. Therefore we restricted our examination to the European continent, and we included all countries where the pandemic appeared in the same temporal pattern, so that European countries with population larger than 200 000 inhabitants except Great Britain and Portugal were all included.

Applying the technique of elastic net regression, we found that both markers of neoliberal and illiberal political orientations had an impact on pandemic outcomes, although their importance varied during the second and third waves of the pandemic.

Results

In the first wave of the pandemic we did not find any impact of the structural variables. During the second wave all markers of democracy indicators show a strong relation with the pandemic outcome. Less extra mortality appeared in more democratic countries and in states with higher social expenditure. In the third wave among the democracy indicators better achievement regarding “rule of law” and higher healthcare spending showed the strongest association with better mortality outcome.

Furthermore, excess mortality was negatively associated with life expectancy and GDP. The intensity of the usage of pandemic management tools was mostly associated with the macro-level characteristics of the countries, only a few had independent effects on excess mortality. In the second wave public transport restrictions, international movement restrictions and testing was associated with mortality outcome in the expected way (but face covering and school closure was associated in higher mortality) but none of the pandemic management tools had an independent effect during the third wave. The same analysis regarding the fourth wave is in preparation

Covid-19 as a catalyst for anti-institutionalist ‘careers’

Tim van Meurs (University of Amsterdam)

Introduction

During the COVID-19 pandemic, anti-institutionalism seemed to have transitioned to the mainstream. Whereas aversion to (establishment) politics, science, and related institutions has been around for years, it had not resulted in a such a consistent stream of (large-scaled) protests and explicit disregard for official health advice. While anti-institutionalism aligned with gradual formation of personal beliefs (e.g., political beliefs) is likely to

remain a deep-rooted sentiment, the COVID-19 pandemic was an extraordinary occurrence that appeared to have quick-started this process. This was evident from the various groups in society that were not previously (vocally or actively) involved in anti-institutionalist discourses, but were during COVID-19. As a Dutch news article stated: “from militant anti-vaxxers to extreme right-wing groups, from peace-loving yoga moms to football hooligans, and from apolitical but concerned citizens to supporters of the [right-populist] Forum for Democracy”.

Two questions remain: first, what made the COVID-19 pandemic such a specific event that it incentivized anti-institutionalism in citizens among which it was previously non-occurrent? Second: can this become a catalyst for further anti-institutionalist ‘careers’, or was it a case-specific phenomenon that declined together with COVID-19-related discourse in media and public life?

For some, the pandemic may have been a ‘wake-up call’ to become more critical of official institutions. For other, COVID-19-induced anti-institutionalism could be more fleeting. Institutional acting during the pandemic was relatively severe, playing a more central role in citizens’ daily lives. Yet, after the measurements were lifted, citizens’ discontent might have decreased again. Following this line of thought, it would imply that anti-institutionalism that ‘awoke’ during the pandemic, now lies dormant.

Methodology

I conducted, and will continue to conduct, in-depth interviews with Dutch citizens that, according to themselves, first developed feelings of anti-institutionalism during the pandemic. I focus on how and why the pandemic caused interviewees to become anti-institutionalist, and on the form this took during, but especially after the pandemic’s heydays.

A share of interviewees is recruited via Telegram groups related to ‘alternative media’ (e.g., blckbx) or COVID-critical groups (e.g., Viruswaarheid). Unlike other social media platforms that actively countered COVID information not in line with official channels, Telegram “will not block anybody who peacefully expresses alternative opinions” (Telegram FAQ, n.d.). In addition, Telegram has been fundamental in various situations of protest mobilization, and sharply increased its user-base during COVID-times in the Netherlands. As such, it seemed the most applicable platform for initial interviewee recruitment.

However, for citizens that were actively anti-institutionalist during the pandemic, but are no longer so post-COVID, these Telegram groups will likely not be a successful way of recruiting. To reach these citizens, I aim to ask interviewees from the initial recruitment to refer me to someone in their social network that they know was, but no longer is involved in a COVID-critical movement. If this proves unfruitful, I will distribute flyers in public spaces (e.g., supermarkets, neighborhood centers) advertising my interest in talking to citizens who “were made critical by the way the COVID-19 pandemic was handled”.

Interviews will be conducted in the way interviewees prefer; either online or in-person. In the case of in-person interviews, I will travel to locations of their choosing. At the time of writing, five interviews have been conducted; twice via videocalls, twice in the interviewee’s home, and one at a public location.

Results

Early interview results point to feelings of uneasiness with the way the pandemic was handled too similarly all across the globe. Interviewees indicated that the measures that were put in place were too unrealistic and seemed ‘planned’. In addition, there was a general belief that we are not yet in a ‘Post-COVID’ era, as the way non-conforming citizens were treated will leave a gap between the institutions themselves that enlarged and may not easily narrow.

Interviews will reconvene in February 2024, with the second interview phase being planned from April 2024 onwards. These waves of interviews will take place after the most recent national elections, in which the right-

wing, anti-establishment Party for Freedom (PVV) gathered most votes. This might have been in (in)direct response to institutional acting during the pandemic, and will have to be discussed during the interviews.

Conclusion

The impact that the COVID-19 pandemic had on citizens' worldviews will remain a question, but it is inconceivable that institutions come out unscathed. This study aims to uncover why the pandemic formed a 'wake-up call' for various groups of citizens to become anti-institutionalist. More importantly, it attempts to reveal the ways in which the pandemic, and institutional acting during it, might have opened up the way for citizens to embrace a wider anti-institutional stance. In this, I attempt to discuss, too, why the pandemic caused longer-lasting anti-institutionalism in some, and only case-specific anti-institutionalism in others, providing an insider's view on citizens that are generally considered as 'outsiders' of society.

Monolithic medicine: Vaccine hesitancy and the 'pharmaceutical solution' in the Philippines

Vincen Gregory Yu (University of Sydney)

Vaccine hesitancy—the phenomenon by which individuals delay or refuse immunizations—is often discussed alongside and unfairly dismissed as plainly rooted in belief in conspiracy theories. One theory that prominently figured in these discussions throughout the COVID-19 pandemic painted vaccines as profit-boosting instruments designed to merely enrich the pharmaceutical manufacturers that sold them to world governments; in other words, vaccinations as embedded in a capitalistic healthcare system and politico-economic context (Sobo, 2021). Ideas regarding the dominance in health care of that entity known as Big Pharma have not been unique or limited to the pandemic, of course: They have arguably grown alongside discussions of pharmaceuticalization and power (Abraham, 2010; Edgar, 2012). In the same vein, vaccinations themselves have been situated in other (interlinked) contexts of contestation or controversy—for instance, notions of 'vaccine apartheid' in low-income countries during the pandemic (Paquin & Plouffe-Malette, 2023). While it is easy to relegate people's anxieties and apprehensions toward the pharmaceutical industry and vaccinations to the realm of misinformation, the literature is rife with accounts that, at the very least, shed light on the possible, valid origins of such sentiments.

This presentation adds to that body of work by demonstrating how vaccine hesitancy can be shaped not just by passively acquired suspicions toward Big Pharma, but, more significantly, by intimate encounters with the health system itself and the confluence of ideas springing from such encounters. Drawing from thematic analysis of 33 qualitative interviews with individuals who identified as vaccine-hesitant in the Greater Manila region of the Philippines, this presentation illustrates the figurative *and* literal journey through which a person can start out identifying as pro-vaccine and end up doubting those same vaccines—a journey that involves encounters with disease and biomedical cures, and the pharmaceutical and Western medical establishments, as well as parallel encounters with alternative and traditional systems of healing. Vaccine hesitancy, in this case, is founded not on conspiracy theories, but on first-hand glimpses into the workings of medical systems and experiences during the pandemic. Specifically, vaccines are perceived as having assumed a 'monolithic' or 'monocultural' status, pushed by the powers-that-be as the one and only solution for COVID-19. Concurrently informing this view are beliefs, either substantiated or not, of how systems of cure and disease prevention work, and what their ideologies and intentions supposedly are—including notions of Big Pharma, Big Food, and Big Agri(culture).

By articulating this idea of a monocultural pharmaceutical solution to the pandemic, this presentation provides an avenue for further reflection into the kinds of health interventions that find favor among authorities, gain traction in society, and earn the trust of citizens—as the well as the kinds of interventions that do not. It calls into question the methods of health leadership, governance, and regulation that dictate the treatments that become accessible to communities. It interrogates the successes and pitfalls of our collective pandemic response, in which vaccines dominated the discourse over other, more accessible public health measures such as masking and ventilation. Finally, it creates a space not only for imagining alternatives to medical solutions, but also for understanding contradictory views to that which we generally accept as 'empirical' and 'scientific'.

Social Inequalities in Healthcare Use, Thematic Session - Chair: Murtaza Mohiqi – Room K.201

Barriers to health services for residents in underserved wards in East and West Birmingham

Alexis Paton (Aston University), Céline Benoit (Aston University)

Introduction

Access to health services is experienced unequally throughout Birmingham. Following the principles of the inverse care law, residents of some of the most deprived wards of Birmingham often have the least health services available to them, precluding them from living as healthily as possible. In this presentation, we discuss the Health inequalities in Birmingham Project, a collaboration between Aston University, Birmingham Community Healthcare NHS Foundation Trust (BCHC), and Citizens UK to better understand the lived experience of residents trying to access their local primary health services.

Methodology

The project used an innovated methodology of health listening to better understand health inequalities in some of the most deprived wards of East and West Birmingham. That information was used to launch a series of co-produced initiatives, funded by the project partners, to help tackle some of the barriers that lead to poor health outcomes in these areas.

The team held five listening events with residents from underserved and deprived communities in East and West Birmingham to understand local challenges to accessing health services. Local community centers and groups facilitated residents to attend, providing space, refreshments and space for children to play. At these events residents outlined in detail their issues accessing healthcare in their community and the impact this has on their health and wellbeing.

Results

The biggest barriers to healthy living and accessing health services residents identified included:

- GP accessibility
- Language barriers and lack of suitable translation/interpretation services available
- Lack of continuity of care
- Inadequate support and provision for children and young people services

Other barriers to health services were related to wider social and structural determinants that affected general health and wellbeing because these are areas of deprivation. Including:

- Local Authority closing down local sports centers and swimming pools in underserved areas
- Lack of investment to support voluntary, community, faith and social enterprise
- Poverty and cost of living concerns
- Digital exclusion

Conclusion

Working directly with community groups from those wards, we then hosted a community sandpit event to co-produce solutions to respond to these challenges. As a result of this initiative, five follow-up projects were funded to support health and wellbeing among local residents. We end this presentation with a discussion of these projects, the positive outcomes on health to residents these follow-up projects have had and three recommendations to health and social care providers to improve provision and access of services in these areas.

The project serves as an example of how using our innovative health listening approach can provide targeted solutions to issues of health and social care access in different communities.

Health Information- and Healthcare Seeking Behavior among Diverse Women and Men with Ischemic Heart Disease

Bryn Hummel (Amsterdam UMC), Dinah van Schalkwijk (Tilburg University), Paula Mommersteeg (Tilburg University), Ralf Harskamp (Amsterdam UMC), Mustafa Bulut (Elisabeth Tweesteden Ziekenhuis), Harriëtte Verwey (Leiden UMC), Irene van Valkengoed (Amsterdam UMC)

Introduction

Timely diagnosis and treatment of ischemic heart disease (IHD) is associated with better outcomes and lower mortality rates. Despite improvements in survival over recent years, mortality is still higher in women, people from some ethnic minority groups, and people with a lower socioeconomic status (SES). A possible explanation is that people within these subgroups are more likely to experience patient- and system delays in seeking and receiving care, which may be related to health information- and healthcare seeking behavior. Therefore, this study aims to examine factors driving these delays, in women and men of different ethnic groups and with a lower SES.

Methodology

We conducted 32 qualitative interviews with patients of different ethnic backgrounds (including Dutch, South-Asian Surinamese, African Surinamese, Turkish, Moroccan, and other ethnicities) between the ages of 30-70, who had received a first IHD-diagnosis in the past 5 years. We asked patients about personal characteristics (gender, ethnicity, SES), symptom presentations, barriers and needs related to healthcare- and health information seeking behavior, and communication with healthcare professionals (HCPs). Next, we conducted one focus group and seven interviews with key figures from different ethnic groups and several HCPs, and eight focus groups with non-patients from different ethnic groups, to validate patient interview findings, and gain insights into populations not reached. Moreover, we explored HCPs perspectives on patient- and system delays. After verbatim transcription, we conducted a thematic analysis of the interviews and focus groups, which were checked by a second researcher.

Results

We found minimal variation in health information seeking behavior, as most patients did not look up information about symptoms (online) before contacting their HCP. Health information seeking behavior was mostly limited to those with greater health literacy (e.g. experience working in the medical field). This was true for women and men across all ethnic groups. Most people preferred discussing symptoms with their HCP over seeking (online) information, which was in part related to low (digital) literacy and risk of possible misinformation. With respect to healthcare seeking behavior, we found several different care seeking barriers. Symptom recognition in particular affected healthcare seeking behavior: those who suffered from more prodromal, intermittent, less intense, or atypical symptoms, frequently delayed seeking care. This applied to women and men across ethnic groups. Other barriers included sex/gender-related factors (e.g., patient-physician sex (dis)concordance, gender roles), cultural factors (e.g., cultural expectations of care, communication differences between patients and HCPs, home remedies), religion (e.g., seeking spiritual instead of medical care), financial barriers (e.g., high (perceived) costs), and fear. These barriers applied to women and men of most ethnic groups, with the exception of cultural and religious barriers in native Dutch participants. Findings were confirmed by key figures and non-patients. The most common triggers to eventually seek care were a deterioration or continuation of symptoms, as well as pressure from patients' social network to seek care. Patients, key figures and non-patients mostly attributed possible system delays to factors within the healthcare system. These included long wait times, HCPs not recognizing symptoms at first, and diagnostic tests coming back negative. HCP perspectives were largely in line with these findings, yet, they emphasized difficulty in diagnosing IHD in primary care, given the various nature of symptoms and the financial and time constraints.

Conclusion

Our results indicate a need for accessible gender- and culturally sensitive information provision to improve symptom recognition and remove the barriers to care identified in this multi-ethnic population. As currently available (online) information may not be appropriate, further research should elucidate how information should be provided in order to effectively reach these communities. Moreover, to reduce possible system delays, development and implementation of low-cost and efficient diagnostic strategies to rule out IHD in primary should be prioritized.

Access to digitalized primary care: Intersectionality-informed narratives from minoritized ethnic communities in the UK

Farjana Islam (Heriot-Watt University), Sara Bailey (The Open University), Gina Netto (Heriot-Watt University)

Introduction

The value of intersectional approaches in addressing multiple discriminations and oppressions as well as positions of privilege in healthcare is gaining increasing recognition (Gkiouleka et al., 2018, Heard et al., 2020). However, frustratingly, ethnicity has remained a neglected parameter in efforts to ensure equitable health outcomes (Chouhan and Nazroo, 2020) despite evidence of poorer health among some minoritized ethnic (ME) communities (Marmot et al, 2020) and lower satisfaction with GP services (NHS England, 2023). Such disparities provide a compelling argument for greater attention to access and contact with GPs among ME communities. GPs play a key role in early diagnosis of illness, treatment, and referring patients to specialist services (Sripa et al., 2019).

As part of the transition to a 'Digital First' approach, individuals seeking GP appointments are increasingly expected to use online booking systems and engage in online consultations. However, worryingly, limited attention has been paid to digital inclusion as a social determinant of health (Chidambaram et al., 2024). The Topol Review (2019) has highlighted the risk of increased racialized exclusions due to the lack of resources and capacity to engage with digitalized health services among ME communities. Further, current understanding of how individuals' ethnicity interacts with other dimensions of inequality, such as age, gender, religion, and income to influence access to healthcare services is limited. Our paper takes a critical realist approach to intersectionality (Archer, 2003; 2007) and builds on Levesque's et al. (2013) patient-centered access framework to explore the risk of exclusion of individuals from ME communities from digitalized primary care services.

Methodology

We carried out 100 interviews with ME individuals from four case study sites (Manchester, Bradford, the London Borough of Tower Hamlets and Glasgow) to capture the complex challenges experienced by ME communities in accessing and using digitalized health platforms. A purposeful sampling strategy was employed to recruit the ME groups which were most at risk of digital exclusion and racialized discrimination due to their disadvantaged socio-economic status and visibility, namely Bangladeshi and Pakistani communities (Marmot et al, 2020) and African, Caribbean, Indian and Chinese groups. We also purposively sampled from three age groups: young (18 to 35) middle-aged (36 to 64) and old (65 and above). The majority were women (60%). All collected information was anonymized, coded in NVivo and thematically analyzed by identifying clusters of 'enablements' and constraints (Archer, 2003 and 2007) and drawing on Levesque's et al. (2013) five dimensions of accessibility, namely: ability to perceive, ability to seek, ability to reach, ability to pay and ability to engage with digitalized healthcare.

Results

Participants' engagement with digitalized primary care services ranged from complete digital inclusion to complete exclusion. The lack of adequacy of alternative channels, such as phones, indicates that some individuals were not only at risk of digital exclusion but of being entirely excluded from primary care services. Engagement with services was in many cases facilitated by clusters of enablements including access to adequate digital devices, affordable data, informal support, bilingual staff and practitioners who were willing to use alternative

channels such as phones. Conversely, clusters of constraints often operated to prevent engagement. For instance, most ME individuals categorized as old had completely withdrawn themselves from independently using digital services due to language- and literacy-related barriers, lack of access to digital devices and limited digital literacy. In contrast, some young people with high degrees of digital literacy who were proficient in English reflected that they preferred to use online services to minimize the risk of encountering racialized attitudes of staff.

Individuals across all age groups on low income struggled with the affordability of digital services since this involved possession or access to digital devices with sufficient memory space and paying for mobile data. Some young and mid-aged individuals experienced challenges in completing online forms to communicate symptoms due to limited proficiency in English and digital literacy, revealing only partial engagement with online services. People with darker skin reflected that some health professionals' over-reliance on photos at the booking stage may hinder their ability to access timely treatment due to lack of visibility of their symptoms.

Gender intersected with age and ethnicity in participants' ability to book appointments among female participants, some of whom had to share a device to secure a GP appointment for themselves, as well as others, particularly in multi-generational households.

Conclusion

The rapid transformation of primary care services has, in many cases, presented new challenges to individuals from ME communities in engaging with primary care. While some examples of good practice have emerged, overall, little attention appears to have been paid to enabling individuals to overcome multiple barriers. Greater recognition of the differential abilities of individuals from ME communities to engage with online services is urgently needed to ensure more equitable access to primary care in the UK.

Mitigating Health Disparities: Unraveling Systemic Injustices in Healthcare through Human Rights-Centric Strategies

Murtaza Mohiqi (University of South-Eastern Norway)

Introduction

Health disparities persist globally, highlighting pervasive systemic injustices within healthcare systems. These disparities are deeply rooted in social, economic, and political structures that disproportionately affect marginalized communities. This extended abstract explores the nexus of health disparities and human rights, aiming to unravel systemic injustices in healthcare and propose strategies for mitigation. The literature reveals a complex interplay of factors contributing to health disparities, including socioeconomic status, race, gender, and access to healthcare resources. Systemic biases, discrimination, and inequitable distribution of health services further exacerbate these disparities. Recognizing healthcare as a fundamental human right, it is imperative to address these systemic issues to ensure equal access to quality healthcare for all.

Methodology

This research employs a multidisciplinary approach, integrating qualitative and quantitative methods to comprehensively analyze health disparities. Qualitative data collection includes focus group discussions, and content analysis of relevant documents to capture the lived experiences and perceptions of marginalized communities. Quantitative data involves the analysis of health indicators, socioeconomic factors.

Results

Preliminary findings underscore the pervasive nature of health disparities, revealing stark differences in health outcomes across diverse populations. Factors such as income inequality, racial discrimination, and inadequate healthcare infrastructure emerge as key contributors to these disparities. Analysis of qualitative data illuminates

the intricate ways in which systemic injustices manifest in healthcare delivery, impeding access and perpetuating inequalities.

Conclusion

In conclusion, addressing health disparities requires a human rights-centric approach that dismantles systemic injustices embedded in healthcare systems. This research contributes to the understanding of the intricate mechanisms perpetuating disparities and underscores the urgency of adopting strategies rooted in human rights principles.

The proposed strategies include policy reforms, community engagement, and healthcare system restructuring to ensure equitable access to healthcare resources. While the study sheds light on the complexities of health disparities, it acknowledges limitations, such as the evolving nature of healthcare systems and the need for ongoing research.

In summary, mitigating health disparities necessitates a paradigm shift towards a human rights-centric framework, promoting inclusivity, justice, and equal access to healthcare for all. This research serves as a foundation for further exploration and action, urging stakeholders to collaborate in the pursuit of a more equitable and just healthcare landscape.

Preventive Health (Inequalities): Enhancing our Understanding through Adopting Sociological Theories, Thematic Session – Chair: Katrijn Delaruelle – Room K.202

Attitude towards vaccination as a trust-based concept: The effects of interaction between parents and healthcare professionals

Alice Scavarda (University of Turin), Mario Cardano (University of Turin), Luigi Gariglio (University of Turin)

Abstract

In this talk, we will first present our contribution to the literature on childhood vaccine hesitancy, focusing on the interaction between parents and health professionals, and how trust and vulnerability are intertwined in this context. Secondly, we will present some case studies from the team ethnography conducted in local vaccination centers and pediatric clinics as part of the European Horizon 2020 project: "Vax Trust: Tackling Vaccine Hesitancy in Europe". These case studies illustrate how parents' trust in vaccination and in the healthcare system can increase or decrease as a result of multiple interactions with healthcare professionals, and how they can interactively influence each other through contagion mechanisms, in line with Collin's (2004) concept of interaction chains. Finally, we will argue that although vulnerability is reciprocal, since both parents and health professionals are vulnerable to the possible negative consequences of vaccination, the asymmetry of information, as well as the different risks and responsibilities at stake, make parents more vulnerable than healthcare professionals. Trust can therefore be seen as a coping strategy to manage parental vulnerability, which is twofold because it involves both parents in their newly assumed role and their children. In this sense, childhood vaccination can be seen as a critical case study of trust in preventive health care practices.

Scholars approach the issue of childhood vaccine hesitancy from a variety of perspectives (Bussink-Voorend *et al.* 2022; Brunson 2013; Reich 2016; Peretti-Watel *et al.* 2015; Sobo 2016). Although qualitative studies highlight a wide range of factors influencing vaccine hesitancy (see, for example, Diaz-Crescitelli *et al.* 2020; Dubé *et al.* 2013; Dubé *et al.* 2016; Majid, Ahmad 2020), there is an absence at the heart of this diversity of studies, namely the impact of the interaction between parents and health professionals on parental attitudes towards vaccination. This absence, we argue, is due to a theoretical underdevelopment of the influence of trust in the context of vaccination. We contend that vaccination attitudes and behaviors are highly dependent on trust not only in the healthcare system, but also in specific professionals as representatives of an abstract expert system,

in this case the healthcare system (Giddens 1990). In line with Giddens' theorization, we argue that these (healthcare) professionals act as access points to abstract systems (the healthcare system) and that parents' encounters with them shape their understanding of the wider system. Trust, in other words, is shaped by interaction and communication (Brown 2008) in the face of vulnerability and future uncertainty (Möllering 2006).

We will discuss some empirical case studies to show that trust is built in a non-linear way and is also fragile, depending on current and past experiences, emotions and beliefs. On the one hand, parents are socially induced to demonstrate their expertise in line with recent intensive parenting models (Hoffman 2010), which challenge the authority of experts and force parents to take responsibility for their children's health outcomes. On the other hand, healthcare professionals are constrained by both managerialism, which imposes time pressures (for example, the time allowed for a visit to a vaccination center is six minutes), and by consumerism, i.e. the fear of being judged and blamed for mistakes by patients. In addition, new trends such as personalized medicine act as macro-structural elements that can influence the context of interaction. As a result, both parents and healthcare professionals share a state of vulnerability. In the context of childhood vaccination, the vulnerability of parents is accentuated by the fact that they are about to intervene clinically in their child's body, usually when the child is healthy, and may only partially understand the reasons for the preventive practice. People who have just become parents or have children with disabilities or neurodivergence may embody a vulnerable pre-existing condition. Healthcare professionals, especially young trainees, are vulnerable to possible retribution from parents in the event of malpractice or adverse effects. During participant observation, they often talked about how this awareness influenced their work, both in terms of defensive medicine and fear of the unpredictable adverse effects of vaccination. To manage this mutual anxiety, which is more pronounced for parents, both parents and health professionals need to rely on trust. However, the asymmetry of information and parents' primary responsibility for their child make them more vulnerable to the potential adverse effects of vaccination. If this vulnerability is recognized and accepted by healthcare professionals through emotional attunement (*sensu* Collins) and an empathetic attitude, it can have positive effects. Conversely, if healthcare professionals adopt a blaming attitude, parents may feel betrayed by them, and their trust may waver as a result.

Paradoxically, parents and their children become vulnerable by undergoing the vaccination procedure to overcome vulnerability, and in a vicious circle, the more vulnerable they are, the more they need to trust as a way of coping with their condition. The problem may lie in trying to channel this trust of new parents to healthcare institutions rather than to other sources of trust (peers, reluctant professionals, opinion leaders).

Socioeconomic position, cultural health capital and female cancer screening services

Katrijn Delaruelle (Ghent University)

Background

In Europe, cancer in females is a major public health burden and a priority of health policy. Pap smear screening for cervical cancer, mammography screening for breast cancer, and Faecal Occult Blood Testing (FOBT) for colorectal cancer, make it possible to detect and treat these cancers in an early stage, and reduce mortality. Yet, strong inequalities have been observed concerning screening uptake for these three CS services. Little is known about the importance of cultural health capital (CHC) characteristics for engaging in female cancer screening (CS) services and associated inequalities. Within the context of healthcare, CHC refers to the specific set of cultural skills, resources and competencies, which influence the individual's use of healthcare and quality of medical encounters. CHC develops through the repeated enactment of health-related practices, examples of which are consuming biomedical knowledge, exercising calculative and future-oriented approaches to decision-making, and engaging in self-surveillance and risk-reduction practices like screening. CHC becomes directly relevant to health through the adoption of healthy lifestyles, which are among the key mechanisms through which health is socially constructed or influenced, for example through engaging in prevention or not.

Goal

Our aim was to examine the relationship between both socioeconomic and CHC-related characteristics and the attendance to Pap smear, mammography and FOBT uptake, in relation to the availability of organized CS programs in Europe.

Methods

We used data from the European Health Interview Survey's (EHIS) second wave, from 2014. Besides all EU member states, we also included Norway, Iceland and Switzerland, bringing the total number of countries to 31. For Switzerland, data come from the Swiss Health Interview Survey (SHIS) 2012 wave. For the contextual characteristics data were imputed from other sources. Namely, for the countries' screening strategies, data come from the International Agency for Research on Cancer (IARC), and for GDP per capita, data were retrieved from the United Nations Development Program (UNDP). To facilitate comparison of the screening types, we restricted the study population to women aged 50-64 because this age-range overlaps with the recommended age for all three screening types. The final sample consisted of 44,392 respondents. To define CHC, we incorporated indicators referring to primary and secondary lifestyles. For primary prevention lifestyle, a dichotomous variable was constructed based on survey questions inquiring about the respondents' fruit and vegetables intake, and smoking and drinking behavior. For secondary prevention, we constructed three different dichotomous variables based on whether women had engaged in two of the three CS tests within the recommended interval and in blood pressure and cholesterol screening.

Results

Firstly, clear income and educational gradients were found for Pap smear and mammography screening uptake, but not for FOBT. Further, engaging in primary and secondary prevention increased a woman's likelihood of CS uptake, for all three CS outcomes. The positive effect of secondary prevention was lower in countries with organized screening programs (versus opportunistic screening) for Pap smear and mammography screening, but not for FOBT screening.

Conclusion

Our findings suggest that inequalities in CHC substantially contribute to inequalities in CS participation. Nevertheless, organized programs at country level (institutional CHC) may compensate for an absence of both socioeconomic and CHC at the individual level, highlighting their potential to reduce inequalities in CS uptake.

Understanding the social context of regulatory problems: A promising strategy in preventive mental health care

Sara De Bruyn (University of Antwerp), Febe Hertveldt (University of Antwerp), Guido Van Hal (University of Antwerp), Koen Ponnet (Ghent University), Monica Dhar (University of Antwerp), Binu Singh (Catholic University of Leuven), Edwin Wouters (University of Antwerp)

Introduction

The foundational roots of mental health are deeply embedded in early social interactions: Babies come into the world relatively helpless and rely on the help of their caregivers to regulate basic bodily functions, navigate the complexities of the day-night rhythm, manage emotions and regulate attention. The intricate dance between infants experiencing stress and/or overwhelming emotional arousal and the sensitive response of parents to calm their infant and meet the infant's physical and emotional needs as a response, sets the basis for a secure attachment relationship. Over time, the infant internalizes the expectation of the parent's soothing response and is able to increasingly learn self-regulation skills. These early self- and co-regulation processes act as the foundation of one's socio-emotional development.

However, these regulatory processes do not always occur smoothly, and regulatory problems (RP) can manifest in various forms, including inconsolable crying, sleeping, eating and/or attention problems, and/or a higher rate

of tantrums. Studies indicate that infant RP pose a public health concern, with 15-35% of parents reporting infant sleeping problems and 14-28% reporting problematic crying in the first months of a child's life. Approximately 8% of these infants experience persistent RP from infancy to preschool age. This preschool period is critical for the development of self-regulation abilities, influencing later-life outcomes such as social and academic functioning, interpersonal behavior, mental health and healthy living in later life. RP at a young age have been linked to behavioral, socio-emotional and cognitive problems in childhood.

To date, existing (mostly quantitative) research on the risk factors of RP primarily adopts a psychological perspective, focusing on child and/or mother-child dyadic characteristics (e.g., mother's mental health). However, there is a significant gap in understanding the fathers' perspective, as well as the impact of broader sociological factors on infant mental health.

Methodology

This study aims to address this gap through an in-depth qualitative exploration of the experiences of approximately 20 parent dyads with infants and young children (up to two years old) facing RP. We will conduct interviews using a narrative reconstruction approach. Respondents will be both purposively and theoretically sampled (i.e. sampling until saturation). Employing an abductive analytical perspective, interviews will be coded and analyzed iteratively, without a pre-existing coding structure, against the backdrop of relevant (sociological) theories. Interviews will be coded by at least two researchers to ensure intercoder reliability.

Results

Building on theoretical frameworks such as Pearlin's Sociological Stress Theory, Bronfenbrenner's (bio)ecological Model and Tronick's Mutual Regulation Model, we hypothesize that RP are the result of a bidirectional complex biospsychosocial process where both the child and the parents bring unique characteristics into the relationship and can reinforce each other's behavior. For instance, infants experiencing RP, manifested as frequent night waking or excessive crying can cause fatigue, frustration and doubt among parents, thereby leading to intrusive or rejecting parental behavior, which consequently reinforces the child's RP. This cumulative infant and parental fatigue may eventually unleash a dysregulation spiral between the parents and the child. At the same time, infant (and parent) mental health cannot be studied in isolation from the environment in which they grow up. As Pearlin claims, in order to fully and correctly grasp the impact of a particular stressor, such as RP, one should also assess economic, occupational, family, and social stressors. We hypothesize that stressors related to (1) pregnancy/birth, (2) occupation/finances/SES, (3) parents' relationship and/or (4) lack of social/professional support can make parents vulnerable for co-regulation difficulties, possibly influencing the development and trajectory of the infants' RP. By exploring the intricate interplay between these factors, we aim to identify key challenges, concerns and missed opportunities in the evolution of RP within the broader ecological context of the child.

Conclusion

The combination of the growing mental health care burden and the limited human and monetary resources for health stresses the clear need for effective prevention strategies. Recognizing the pivotal role of RP in infancy, this study aims to provide insights into the modulating factors within the child's ecological context. By using a qualitative and multi-family approach, encompassing both mother and father, and considering the meso and macro environment around the parent-child relationship, we seek to disentangle the mechanisms of how the social context might shape (inequalities in) mental health from early on.

Cultural difference in the effect of organized programs on socioeconomic inequalities in breast cancer screening: Ecological study in Switzerland

Stéphane Cullati (University of Fribourg)

Background

It is unknown whether organized mammography screening programs improve breast cancer prevention equally for all socioeconomic conditions within the context of cultural differences. Switzerland has cultural differences and no national program but local organized screening initiatives. Most of the Latin part is covered by regional screening programs, while the German regions still heavily performs opportunistic screening.

Methods

Data on 14,173 women aged 50-69 was drawn from five cross-sectional waves of the nationally representative Swiss Health Interview Survey (1997-2017). Socioeconomic indicators included education, household income and employment status. Poisson regression was used to estimate Adjusted Prevalence Ratios (APR) of up-to-date (last two years) mammography. The analysis was complemented using the Relative Index of Inequality (RII) and the Slope Index of Inequality (SII).

Results

The mean age of the women was 59.3 years (standard deviation (SD) 0.06) in the German and 59.3 (SD 0.08) in the Latin regions of Switzerland. In the period 1997-2017, the prevalence of up-to-date mammography was 36.3% for women living in the German regions and 67.1% for women living in the Latin regions. The mammography screening program did not affect income and employment disparities in mammography across linguistic regions. However, a notable distinction emerged regarding education. In the Latin cantons, the screening program had no impact on socio-economic inequalities in screening. Conversely, in the German cantons, regional screening programs demonstrated an increased impact on women with lower education, effectively reducing education inequities in mammography. Three sensitivity analyzes that replicated the main analysis (1/excluding respondents treated for cancer, 2/ excluding cases from the Italian regions of Switzerland, 3/ excluding mammograms conducted for diagnostic reasons) and the results did not change in a way that would alter the conclusions of our study.

Conclusions

Socio-economic inequalities persist in both German and Latin regions if mammography screening is done in an opportunistic way. Regional screening programs only reduce these inequities in German regions, namely by negating the effect of education on up-to-date mammography rates. Public health agencies should consider potential cultural understandings of preventive exams inherent in Latin and Germanic cultures when formulating strategies regarding breast cancer prevention programs. Considering and addressing the different cultural perception of programs could ensure that breast cancer prevention initiatives are not only effective but do also take into account cultural attitudes across different socioeconomic groups. This might imply moving away from a one-dimensional approach and instead adopting a multimodal approach to organized screening..

Gender and Health Prevention: Questioning, Measuring, Evaluating... Transforming?, Thematic Session – Chair: Joëlle Kivits – Room K.203

Opportunities for gender transformative suicide prevention in adolescents and young adults: A systematic review

Léa Loubet (Université Paris Cité), Joëlle Kivits (Université Paris Cité), Virginie Bonnot (Université Paris Cité)

Introduction

Research in sociology, psychology, and medicine has demonstrated that suicidal behaviors exhibit gendered aspects. Indeed there are differences between women and men in suicidal scripts, prevalence of suicidal behaviors, and help-seeking behaviors. Additionally, risk factors vary often according to gender, with sexual and gender minorities being particularly exposed to violence and stigmatization. Taking into account these specific risk factors can provide key elements for prevention. Moreover, a systematic review of suicide prevention interventions for youth revealed an increase in the development of programs for this group, but a lack of such

programs targeting minorities. The aim of our systematic review was to describe the current use of gender in the suicide prevention and to identify gender transformative approaches. Gender is a crucial issue in public health research, especially in the development of gender transformative approaches to health promotion.

Methodology

The study followed the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA). Three databases were searched using vocabulary related to the *continuum* of self-inflicted violence, intervention concepts, adolescent and young adult population, and gender.

Results

Out of 1446 articles, we selected 141 articles for inclusion. Data was collected on each intervention and the use of gender. According to the framework developed by Pederson and colleagues and adapted here for suicide prevention, 46% of the studies reviewed were gender-blind. Of the remaining articles, 20 (14%) adjusted their statistical models based on a binary category of sex or gender identity without further analysis or results, demonstrating a minor sensitivity to gender. 34 (24%) articles were found to be more sensitive to gender because of a search for gendered effects of interventions. Among these articles, 10 (7%) studies found differences between young women and men, mostly in favor of the former. Explanations ranged from methodological issues to theoretical explanations based on gender socialization (e.g., gender role theory). 11 (8%) articles developed a specific approach focusing on an identified vulnerable population and targeting different risk factors and situations. These populations included young men, young LGBTI+ individuals, and young women. 3 articles (2%) included gender transformative elements, although not explicitly. The authors emphasized the importance of incorporating co-construction methods, employing trauma-informed approaches, and challenging gender roles and norms.

Conclusion

Current suicide prevention interventions do not rest on gender transformative approaches. Our sample included a significant number of gender sensitive studies that focused on differences between young women and men. However, the causes and explanations of those differences were not explored further or included in the programs. Critical suicide studies have emphasized the need for new frameworks to address inequalities and move beyond a solely biomedical approach to prevention. This communication will discuss opportunities for gender transformative suicide prevention for adolescents and young adults based on a literature review.

Changing contraceptive preferences: A qualitative analysis among men and women in Belgium

Leen De Kort (University of Antwerp), Nina Van Eekert (University of Antwerp)

Background

A few decades ago, the contraceptive pill led to a revolution in the reproductive health landscape. The pill was celebrated for giving people – especially women- control over their bodies, not only in terms of reproduction, but also sexual pleasure. Several other methods have since been developed, which gives women more choice in finding a method that fits their personal preferences, but which might also make the choice more difficult/less straight forward. Additionally, although modern contraception methods still contribute to the emancipation of women, there has also been a shift towards a more critical view on these methods. Within heterosexual relationships the burden concerning taking the responsibility for contraception and dealing with the side-effects of the current contraception options weights much more on women. Hence, there is a rising demand to explore possibilities for equal contraceptive responsibility and more tailored contraceptive options for men. While condom use is often a shared responsibility, at the moment only (male) sterilization can give men full responsibility. This could however change if more male contraceptive options would become available in the future. In this regard, knowing how both women and men chose the contraception methods they and their sexual partners use and how their experiences with these methods shape their ‘contraceptive journey’ would be very valuable.

Objectives

This study therefore aims to qualitatively research how both men and women in Belgium experience the process of choosing a contraception method, if this is accompanied by mental burden, and how more possibilities concerning male contraception would change this.

Methods

These topics will be discussed in 9-12 group conversations with sexually active adults without a current pregnancy desire. In every Belgian region (Brussels, Flanders and Wallonia) a group interview with women aged 18 to 25, an interview with women aged 26 to 55, and an interview with men will take place. Additionally group interviews with people with a low socio-economical background will be organized if they are not represented in the general groups. The group interviews will be guided by a questionnaire focusing on peoples 'lived experience', and the interviews will be recorded, transcribed ad verbatim, and coded inductively and thematically.

Discussion

Having a better view not only on which contraceptive methods people prefer, but also why they do or do not want to use certain methods is valuable for both policy makers and health professionals involved in contraception counseling, family planning, etc. The results of this qualitative research could inform future contraception campaigns and provide guidance in contraception counselling and in developing more gender equal policies concerning contraception.

Revealing women's mental health impact on community uplift and inclusive growth: An exploration unveiled

Nabeela Farah (Government College University Faisalabad)

Introduction

Women, traditionally regarded as nurturers, have been instrumental in fostering inclusive growth by driving household initiatives in education, health, economic empowerment and cultural development. Their collaborative ethos uniquely positions them as influential decision-makers to improve society and making decisions within communities. This research delves into the intricate dynamics defining the symbiotic relationship between women's mental health and their pivotal role as catalysts for societal transformation and community uplift. However, this study meticulously investigates the profound impact of prevalent mental health issues, acting as formidable barriers to women's active engagement in community development at large. A myriad of factors, including financial insecurity, work-life balance challenges, gender inequality and relationship issues, compound their vulnerability, impeding their ability to fulfill their roles as agents of positive social change. This paper systematically scrutinizes the multifaceted and interconnected nature of these mental health challenges and their far-reaching repercussions on women's capacity to make informed decisions that resonate across the broader community. Anticipating the post-COVID-19 era, the research foresees a heightened exacerbation of women's psychological and mental health issues, further complicating their contributions to community uplift. By shedding light on this critical intersection between women potential, mental health and community development, the paper aims not only to illuminate challenges but also to advocate for policies and interventions that unleash women capabilities and give them empowerment. Addressing their mental health concerns becomes paramount to unlocking their potential as dynamic drivers of inclusive growth of the society.

Methodology

For the present research, the extensive review of the existing literature was undertaken with an in-depth interviews and focus group discussions with a subset of participants to gain a nuanced understanding of the lived experiences, perceptions, and challenges faced by women concerning mental health and community engagement. Thematic analysis was made to extract key themes and patterns from qualitative data, providing

rich insights into the qualitative aspects of the research questions. Ethical considerations were paramount throughout the research process.

Results

This study examined the multifaceted nature of these mental health challenges and their repercussions on women's ability to make informed decisions that impact the broader community. The research findings reveal a significant correlation between women's mental health challenges and limited community engagement. Financial insecurity, work-life balance issues, and relationship challenges were identified as prominent barriers, hindering their roles as change agents. Post-COVID-19 mental health issues escalated, exacerbating obstacles to community uplift. The multifaceted nature of these challenges underscores the urgent need for targeted interventions. The study emphasizes the vital role of addressing women's mental health concerns to unlock their potential as drivers of inclusive growth, advocating for a holistic approach to foster community well-being and prosperity.

Conclusion

By shedding light on this critical intersection between mental health and community development, the paper aims to inform policies and interventions that empower women, addressing their mental health concerns and unleashing their potential as drivers of inclusive growth. This research advocates for a holistic approach to women's well-being, recognizing its intrinsic connection to the overall health and prosperity of communities.

The association of women's empowerment with HIV-related indicators in sub-Saharan Africa

Theresa Schierl (Technical University Munich), Luana Fiengo Tanaka (Technical University Munich), Stefanie J. Klug (Technical University Munich), Andrea S. Winkler (Technical University Munich), Dominik Stelzle (Technical University Munich)

Introduction

Women are disproportionately affected by HIV; they make up over 60% of people living with HIV globally. This difference is especially pronounced among young women (15-24 years) in sub-Saharan Africa (SSA), where they made up 10% of the population but 20% of new infections in 2018. Women's empowerment is an essential factor for HIV prevention, but the association with HIV-related indicators has never been quantified. In this study, we examined the association between women's empowerment and selected HIV-related indicators in SSA.

Methodology

We used data from the latest Demographic and Health Surveys (DHS) that included HIV testing among other biomarkers of 31 countries in SSA. The timepoint of data collection varies between countries from 2006 to 2018. Empowerment was measured by the Survey-based Women's EmPOWERment (SWPER) index by Ewerling and colleagues. The index was compared to five HIV-related indicators: HIV status, HIV testing (ever and in the past 12 months), condom use at last high-risk sex, the ability to ask the partner to use a condom and the ability to refuse sex. The SWPER consists of three dimensions: attitudes towards violence, social independence and decision-making, which are computed using 15 items with different weights. The decision-making dimension puts most of the weight on decisions at the household level rather than the societal or individual level. It gives relevance to the item "Who makes decisions about the respondent's health", which is crucial for HIV prevention. We examined the association between empowerment levels and the 5 HIV-related outcome variables using logistic regression models and adjusted for age, type of residence and wealth quintile, we used low empowerment as the reference category.

Results

208 947 women were included in the analysis, of whom 100 924 (48%) were considered highly empowered and 21 933 (10%) as lowly empowered. These empowerment levels varied considerably across countries. The median age was 27 years, most women were living in rural areas (69.4%), and a high proportion had no formal education

(44%). Overall, women with higher education were more empowered (79%) compared to those without education (36%). There was no significant association between empowerment levels and HIV status (OR=1.12, 95% CI= 0.98-1.28). Compared to lowly empowered women, highly empowered women were more likely to have ever been tested for HIV (OR=1.67, 95% CI 1.60-1.74) but less likely to have been tested for HIV in the past 12 months (OR=0.92, 95%CI 0.88-0.96). Highly empowered women were more able to ask the partner to use a condom (OR=1.69, 95% CI 1.63-1.75) and to refuse sex (OR=1.78, 95%CI 1.72-1.85) compared to lowly empowered women.

Conclusion

The results of this study highlight the complexity of HIV transmission networks within SSA. Women's empowerment is strongly associated with a woman's ability to make decisions about her sexual behavior. Highly empowered women are more likely to have ever been tested for HIV and be able to ask their partner to use a condom and refuse sex, which are critical factors in long-term HIV prevention. Highly empowered women are more likely to make critical decisions about their sexual behavior, thus having more control over their risk of acquiring HIV. This association between autonomy in household decision-making and safer sex negotiations has been previously described in SSA. To achieve the United Nations' goal of ending AIDS by 2030, women and young girls represent a core demographic for prevention and intervention. HIV prevention and health literacy programs may aim to increase women's empowerment and, in turn, their agency over their health decisions, which may lead to fewer infections, earlier treatment initiation, improved survival, and improved quality of life.

5 July: 13:15 – 14:00

General Assembly – Room K.001

5 July: 14:00 – 15:30

Pharmaceuticalization, Thematic Session – Chair: Melissa Ceuterick – Room K.101

Failure and the perpetual novelty and promise of addiction vaccines

Kristin Barker (University of New Mexico), Christopher Lyons (University of New Mexico), Erin Fanning Madden (Wayne State university), Katherine Rickers (University of New Mexico), Preston Lowe (University of New Mexico)

Studies illustrating the “proof of concept” for addiction vaccines were first published in the 1970s (Bonese et al. 1974; Killian et al. 1978). As originally theorized in this foundational research, addiction vaccines could generate antibodies capable of blocking the brain's absorption of an abused drug, thus blocking the drug's pleasurable effects and curing the addict. Since the emergence of this pioneering research, addiction vaccines have been heralded as potential “game changers” in the treatment of substance use disorders (SUD). Labeled as “novel” and “promising” for fifty years (Ozen and Blume 2019), vaccines for different drugs of abuse are currently at varying stages of development (Hossain et al. 2022). None of these, however, are nearing the stage of market approval (Malik and Agewala 2023). Despite committed research and development (R&D) stretching over half a century, the dream of addiction vaccines remains elusive.

Through our analysis of the international peer-reviewed medical literature, we demonstrate the logics underlying the perpetual novelty and promise of vaccines for SUD in general, and opioid use disorder (OUD) in particular. We do so from a perspective that examines the production of biomedical knowledge and technologies as sociopolitical accomplishments (Clarke et al. 2005; Mamo and Epstein 2014). Our methodological approach, an *interpretive systematic review*, is guided by the following broad questions: How, and with what consequences, are vaccines framed as an effective response to SUD? What definitions of addiction are put forth by the vaccine-

SUD narrative; and, by extension, what questions and concerns are sidestepped or ignored? Answering these questions reveals how biomedical research can simultaneously be riddled with failure, on the verge of game-changing breakthroughs, and staunch guardians of the reigning knowledge paradigm.

We present three key empirical findings, which we maintain underlie the perpetual novelty and promise of addiction vaccines in the face of ongoing failure. First, insofar as theoretical assumptions of addiction vaccines intellectually mirror the ruling addiction paradigm – the brain disease model of addiction (BDMA) – repeated failures are managed as technological rather conceptual problems. Second, these repeated technological failures are met by an entrenched and well-funded commitment to an imperative of just-around-the-corner resolutions, which, by design, constitutes a form of iterative inertia. Third, by espousing an ascetic war on euphoria in a treatment era otherwise shifting toward harm-reduction hedonism, addiction vaccines reflect deep cultural anxieties about pleasure and provide moral motivation for continued R&D.

We use the case of addiction vaccines to engage theoretical questions related to the dynamics of scientific failure. There is nothing novel about ongoing failure in biomedical research. Failure is recognized as ubiquitous in science and especially pronounced in pharmaceutical research (Firestein 2015). Failure is often said to motivate progress. Whooley (2019) complicates retrospective and romantic claims of the progressive quality of failure, even as he foregrounds how failure can be generative in other ways. We draw on Whooley's insights concerning the "hype/disappointment cycle" – hype abounds, until disappointment sets in when the outcome cannot live up to the hype. But hype delivers considerable professional resources, even if disappointment sets in down the road (Whooley 201). In the case of addiction vaccines, the hyped-deliverable has yet to be delivered. Paradoxically, the stalled R&D begets ongoing hype. Not only do addiction vaccine failures perpetuate their own hype as persistently novel and promising, but, in the absence of a would-be challenge from real-world disappointment, it also leaves the *neurobiomedicalization* (Rose and Abi-Rached 2013) of addiction unchallenged.

"Patients, trauma survivors, sweethearts or troublemakers?": Healthcare professionals' discourse on clients of opiate substitution treatment

Lena De Bonte (Ghent University)

Opiate substitution treatment (further abbreviated as OST) is one of the most effective interventions within addiction care. OST refers to a wide range of therapies in which clients are provided with a prescription opioid (e.g., methadone or buprenorphine) that is similar or identical to the illegal substance (e.g., heroin) they typically consume. Despite its proven efficacy in reducing illegal substance use and promoting positive outcomes in other life domains (e.g., improved overall health, social functioning and job opportunities), the treatment continues to face scrutiny as complete abstinence is not necessarily a treatment goal. In previous studies, OST clients reported that they experience stigmatization in various medical settings, like pharmacies, general practitioner's offices and emergency departments. In this presentation, we will explore how a group of general practitioners and pharmacists discursively constructs OST and positions themselves in relation to OST clients.

In-depth semi-structured interviews with 28 pharmacists and general practitioners working in pharmacies, private practices, a community health center, the penal system and drug treatment services in Flanders were conducted. A discourse analysis based on positioning theory of Davies and Harré (1990) was applied to the interview transcripts to attain insight into potentially (de)stigmatizing language used by the participants. Positioning theory focuses on how individuals negotiate and take positions (i.e., a complex and dynamic cluster of rights and duties) within broader historical and social storylines. The theory's application as an analytical lens in this study allows us to explore the rights and duties general practitioners and pharmacists attribute to themselves and OST clients in the context of substitution treatment.

This investigation identified four storylines the participants used to position themselves and OST clients. The medical, psychiatric, biopsychosocial and moralizing storylines are all based on historical explanatory models of

addiction. Even though the use of a storyline varied according to the participants' workplace, they were usually combined during the interviews. Firstly, the medical storyline is based on the notion that addiction is an illness with a neurobiological cause. As a result, participants directed considerable attention to the administration of substitution medication and favored maintenance treatment or slow tapering off. This storyline occurred in nearly every interview across the various studied settings. Secondly, the psychiatric storyline assumed that OST clients are deeply traumatized individuals who use(d) illegal substances as a coping strategy. Therefore, participants who applied this storyline focused on providing emotional support and stabilizing clients through maintenance treatment. This storyline was least prevalent in the data, with only two to three participants, working as addiction specialists in the penal system, applying it. Thirdly, the biopsychosocial model that explains addiction by highlighting biological, genetic, social, cultural, cognitive and psychological factors formed the basis for the biopsychosocial storyline. Within this storyline, participants described OST clients in a destigmatizing manner and assigned them an equal position in the decision-making of the treatment goal and plan. General practitioners working in regular practices and specialized drug treatment centers mostly used the biopsychosocial storyline to position themselves in OST. Lastly, the participants who applied the moralizing storyline attributed opioid dependency disorder to a lack of will power and took an authoritarian, controlling position in OST. This storyline was characterized by several elements of Link and Phelan's (2001) stigma model, like othering, stereotyping, labelling and discrimination. While this storyline was evident in all studied settings, it was particularly dominant in the discourse of pharmacists and general practitioners working in prisons.

To conclude, the four identified storylines were used by participants to define their position and the related rights and duties in OST. The dominant storyline thus shapes the view on and treatment of OST clients in a medical setting. Depending on the storyline the participants applied, they framed OST and OST clients in a (de)stigmatizing manner. These findings confirmed previous descriptions of moralistic approaches to opioid use disorder and the related stigma in clinical settings. Because the moralizing storyline was mostly used by participants with limited expertise regarding OST and who had minimal communication with specialized centers, it is recommended to provide more positive representation and education.

Sweets to the sweet! From BZRA dependence to tapering

Melissa Ceuterick (Ghent University), Pauline Van Ngoc (University of Liège), Béatrice Scholtes (University of Liège)

Background

The overconsumption of sedatives and tranquilizers also known as benzodiazepine receptor agonists (BZRAs) is a worldwide problem. This is particularly present in Belgium, one of the countries with the highest consumption and prescription rates of BRZA. Use that exceeds two to four weeks is discommended due to undesirable effects such as tolerance and physical and psychological dependence, and has also been associated with accidents, falls and cognitive problems. Nonetheless, it is estimated that one in every three users still takes the medication continuously after eight years. Furthermore, BZRA are also often combined with other psychotropic medications (like SSRI's).

Entangled in both discourses and social practices, psychotropic medications not only act on bodies but also on subjectivities. Specific aspects of embodiment -such as the consumption of psychotropic medication- are embedded in discursive webs of associations from which health identities are constructed. So far, little is known on the experiences of patients who decide to discontinue BZRA after using this medication longer than recommended and how this is related to (shifts in) their health identities.

Objectives

This paper aims to explore: 1) how long term users of BZRA position themselves in relation to the pharmaceutical-psychotropic self/ imaginary duality related to long term use of this medication, 2) how patients construct their

decision to discontinue the medication, 3) which health identity mechanisms that lead up to cessation and 4) how they describe their cessation trajectories and their experiences with different health care providers.

Methods

A total of 19 in-depth interviews were conducted with people who use BZRA longer than recommended for myriad reasons. The sample varied in gender, age, living place (Flanders, Wallonia), duration of use, reason for use and concomitant use of other psychotropic medication. All interviews were transcribed in the original language. A discourse analysis inspired by Davis and Harré's positioning theory was conducted, with the aid of NVivo. These data were collected as part of a larger study, named BENZOCARE on accessibility of health care for people suffering from different gradations of BZRA dependence (funded by BELSPO).

Results

As the title suggests, former users hold ambiguous feelings towards BZRA. Like the sweets in Shakespeare's Hamlet -which actually refer to funeral bouquets laid on Ophelia's grave- BZRA are far from an innocent indulgence or the sweets they are often ironically compared with. Although many patients tend to start medication without fully realizing this. Cessation is often an arduous trajectory, that does not always follow the straightforward schedule provided by health care professionals. Shifts in medication use are often embedded in what Cockerham calls healthy lifestyle choices, which are not only identity-infused, yet also constrained and steered by structural factors and circumstances. The latter is particularly apparent in the crucial role that health care providers play a) in the discontinuation process (at worst indirectly through their absence, at best by their active engagement and support) and b) to a larger extent also in the (co)construction of taperers' health identities. These results point towards a need for more information and training on particularly difficult tapering trajectories for (future) health care professionals.

'When the psychiatrist gives you medication; you must take them': Lived experience of long-term users of benzodiazepine receptor agonists regarding their treatment

Pauline Van Ngoc (University of Liège), Jean-Luc Belche (University of Liège), Melissa Ceuterick (Ghent University), Béatrice Scholtes (University of Liège)

Introduction

Benzodiazepine receptor agonists (BZRA) are prescribed for hypnotic and antiepileptic effects. However, long-term use (≥ 6 months) can lead to dependence, cognitive impairment, and increased injury risks. Reducing poses challenges, often causing withdrawal symptoms such as anxiety and insomnia resurgence. Guidelines recommend cautious use, suggesting treatment durations between 1 to 4 weeks. However, prescriptions frequently extend beyond this, deviating from these recommendations. Patients' lived experiences are crucial for comprehending the nuances and complexities of withdrawal. Considering the unique challenges associated with withdrawing from BZRAs, gaining a more profound insight into the experiences of patients could prove advantageous for both healthcare professionals and individuals undergoing withdrawal. In this study we explore the experiences regarding their treatment goals of long-term BZRA users who have subsequently either stabilized, reduced, or discontinued their usage.

Method

A purposive sample of long-term BZRA users was recruited, emphasizing diversity in experiences and geographic locations. Interviews, conducted in person or via videoconference, explored participants' journeys, by using a modified life history calendar. The life history calendar prompts individuals to provide detailed information about various life events and their associated contexts along a timeline. This methodology proves reliable for collecting retrospective data, offering a valuable tool to study the timing and sequencing of events while enhancing participants' recall and reporting accuracy. The topic guide was structured into several sections focusing on the management of patients from their initial prescription, their trajectory, the moment they decided to stop, reduce, or stabilize their dose, triggering factors for starting deprescription, and their recovery. Nineteen

interviews, conducted in French (PVN) and Dutch (MC), were analyzed using Interpretative Phenomenological Analysis (IPA). This approach requires an in-depth exploration of participants' lived experiences, aiming to uncover the ways in which they make sense of their experience.

Results

Two superordinate themes surfaced during the data analysis: (1) 'I haven't discussed anything with anyone' and (2) 'I wasn't ready [for the withdrawal]'. Within the first superordinate theme, the findings indicate that patients expressed a desire to take charge of their own decisions independently regarding withdrawal, without healthcare professional involvement. Some of them started to stop BZRA use on their own and informed their GP afterwards. Within the second overarching theme, some patients explained that they felt a strong sense of obligation to adhere strictly to the treatment and prescribing guidelines set out by their healthcare providers. Other participants revealed dissatisfaction due to perceived inadequate education on withdrawal symptoms. Some participants expressed a lack of comprehension regarding the prescriber's therapeutic decisions and highlighted challenges in BZRA withdrawal, underscoring the necessity for personalized reassessment. They emphasize that tapering off requires prior patient's preparation.

Conclusion

Understanding the lived experiences of long-term BZRA users highlights the importance of a patient-centered and goal-oriented care approach, emphasizing patient preferences and needs during their treatment. Strengthening the patient-physician relationship are key elements for addressing dissatisfaction and improving personalized reassessment in BZRA withdrawal process. Ongoing evaluation and adaptation are essential to achieve lasting improvements in support for long-term withdrawal. Focusing on the patients' priorities and needs will not necessarily lead to withdrawal, which may be reevaluated along the way depending on the evolution of the patient's situation. Support is broader and can include withdrawal, and withdrawal is not necessarily included in the support. Recognizing patients' unique perspectives and needs is essential for fostering inclusive healthcare practices, taking into account the impact of diverse social identities.

Mental Health, Regular Session – Chair: Sara De Bruyn – Room K.102

Reducing mental health inequalities between renters and homeowners by potential interventions on financial strain

Daina Kosite (Erasmus MC), Maria Gültzow (Max Planck Institute for Demographic Research), Mariëlle Beenackers (Erasmus MC), Frank van Lenthe (Erasmus MC), Joost Oude Groeniger (Erasmus MC)

Introduction

Housing tenure has long been associated with disparities in mental health outcomes, with renters often experiencing higher levels of psychological distress compared to homeowners. Financial strain is recognized as a key factor contributing to these disparities, as renters may face greater economic challenges and instability. Despite this association, the potential effectiveness of interventions targeting financial strain to alleviate mental health inequalities between renters and homeowners remains underexplored.

Aims

We investigated the potential impact of hypothetical interventions targeting the reduction of financial strain on the observed inequality in mental health between housing tenure groups – renters and homeowners.

Methodology

We used longitudinal data from the GLOBE study, based in Eindhoven, the Netherlands from the years 2011 and 2014 (n=2400). Causal mediation analysis was employed as a methodological framework to assess the interventional impact of reducing or eliminating financial strain on mental health disparities. A marginal

structural model with inverse probability weighting was applied to obtain interventional analogues for controlled direct effect and natural direct effect.

Results

Our findings revealed a significant difference in mental health scores between renters and homeowners, with renters exhibiting an average mental health score of 5.3 (95% CI = 3.73, 6.34) points lower on a 100-point scale. The controlled direct effect interventional analogue suggested that complete elimination of financial strain could lead to a 22% reduction in the observed mental health disparity between renters and homeowners. The natural direct effect analogue indicated a 14% reduction in mental health inequality under a hypothetical intervention where the distribution of financial strain among renters is set to that of the homeowners.

Conclusion

Our study illustrates that addressing financial strain may substantially reduce the inequality in mental health outcomes between renters and homeowners. The application of causal mediation analysis, specifically the controlled direct effect and natural direct effect analogues, offers a novel and promising methodological approach for evaluating the impact of potential interventions on health disparities. These findings contribute to the development of future targeted interventions aimed at alleviating mental health disparities associated with housing tenure.

Anxiety and its major risk factors among the Ukrainian female refugees in the Czech Republic

Iryna Mazhak (RCSI University of Medicine and Health Sciences)

Introduction

More than 500,000 refugees from Ukraine were granted "temporary protection" in the Czech Republic after Russia invaded Ukraine on a large scale in 2022. Due to the numerous stressful situations that refugees must deal with, mental health issues have been rising in this population.

Methodology

This cross-sectional study used an online survey in the Ukrainian language to gather data from 919 Ukrainian female refugees living in the Czech Republic. The survey was distributed through non-governmental organizations that assist refugees, schools in the Czech Republic that educate Ukrainian children, and social media where Ukrainian refugees participate including Facebook, Telegram, and Viber. Data collection took place between June and September 2022.

Anxiety symptoms were measured by using the Beck Anxiety Inventory (BAI), which is a 21-item self-report questionnaire, created by Beck and colleagues (Beck et al., 1993) to measure typical anxiety symptoms separately from depressive symptoms (Beck et al., 1988).

Linear regression analysis was performed to investigate the associations between anxiety and self-reported physical and mental health determinants adjusted by socio-demographics. Depression was included as a covariate in the regression analysis because prior studies showed a correlation between depression and anxiety. Depression was measured by applying the Patient Health Questionnaire (PHQ-9). The PHQ-9 was developed as a screener for depression (PHQ-9; Kroenke et al., 2001). Additionally, perceived stress and coping strategies were also included in the analysis. Perceived stress was measured by the Perceived Stress Scale (PSS-14) which was invented by Cohen, Kamarck, and Mermelstein (1983). PSS-14 measures how people assess the degree of control they have or do not have over unpredictable, unmanageable and overburdened events in their lives (Cohen & Williamson, 1988). The BRIEF-COPE inventory (Carver et al. 1989) was employed to investigate coping strategies for stressful events.

Results

The respondents' average age was 38 years, and 68.4% of them were married; 70% with children under the age of 18. 71% of participants were university graduates, 86.7% of participants have lived in Ukrainian cities and towns, and 73.8% of participants have worked in Ukraine. It was revealed that more than half of the participants had moderate (31.3%) to concerning (22.1%) symptoms of anxiety. Also, it was found that 25.5% of participants had moderate, 17.5 % had moderately severe, and 10.4 had severe levels of depression. Further, Ukrainian female refugees in the Czech Republic experienced moderate (75,2 %) to high (20.3 %) levels of perceived stress. Moreover, participants reported using emotion-focused coping (managing feelings and thoughts related to the stressor) and problem-focused coping (dealing with stressor sources) more frequently than avoidant coping (avoiding dealing with the stressor or associated emotions).

The conducted analysis showed that cultural differences in relationships and communication between Ukrainian female refugees and the Czech population, self-reported poor physical health, and self-reported poor emotional and psychological statuses were major risk factors for anxiety. On the contrary, being employed, and having good relations with relatives, colleagues and neighbors were protective factors. Besides, it was proof the a positive association between anxiety and depression.

Conclusion

The study showed that more than half of Ukrainian female refugees in the Czech Republic experienced moderate to concerning symptoms of anxiety, also, there are some risk and protective factors of anxiety as well as comorbidity with depression. These findings have potentially important public health implications.

Loneliness and its association with subsequent mental health problems in young people

Karina Grigoryan (Stockholm University), Viveca Östberg (Stockholm University), Jonas Raninen (Karolinska Institute; La Trobe University), Sara Brolin Låftman (Stockholm University)

Introduction

Given the overall prevalence of loneliness and its adverse implications for health, it is acknowledged as a global public health concern (Taylor et al., 2023). Multiple studies have demonstrated its detrimental effects on adolescent health across various countries (e.g., Stickley et al., 2016; Lyyra et al., 2021). Specifically, there is growing evidence indicating a rising prevalence of loneliness among the adolescent population in the Nordic countries (Bartelink et al., 2021; Lyyra et al., 2022; Parlikar et al., 2023). Frequent and continued experiences of loneliness can exert an even more detrimental impact on adolescent health (Qualter et al., 2013). This impact may be particularly pronounced during the transition from adolescence to young adulthood—a period characterized by numerous social changes and recognized as vulnerable in terms of social relations (Lee et al., 2018). Furthermore, Hutten et al. (2021) illustrated in their study that one of the trajectories of loneliness from childhood to young adulthood was characterized by a peak in loneliness around the transitional period from adolescence to adulthood. Although many studies investigated the relationship between loneliness and mental health, few studies have specifically focused on this transitional period, examining a wide range of indicators of mental health problems. Utilizing data on mental health problems from both self-reports and register information can provide a more nuanced understanding of this relationship, representing a merit of the current study. Although the importance of studying loneliness in this life stage has been recognized, majority of prior studies rely on cross-sectional data. Therefore, there is a call for longitudinal studies. Beyond the opportunity to explore temporal associations, longitudinal data also enables the examination of changes in loneliness over time. The *aim* of this study is to examine the associations between loneliness and various subsequent mental health problems among young people, transitioning from late adolescence to young adulthood. In addition to exploring a diverse set of indicators for mental health problems, the current study will examine changes in loneliness over time and its association with subsequent mental health problems.

Methodology

The data is derived from Futura01, a national Swedish cohort study that included adolescents attending grade 9 in 2017 (~15–16 years). Follow-up surveys were performed in 2019 (when respondents typically attended the second grade of upper secondary school; ~17–18 years) and 2022 (~20–21 years). In the current study, self-reported information on loneliness, psychosomatic complaints, and depression and anxiety symptoms was utilized from two survey waves conducted in 2019 and 2022. Furthermore, this information was linked to registry data on in-patient and out-patient care, medication use and sociodemographic characteristics. That resulted in a study sample of [n~2000, *preliminary number*]. Loneliness was assessed using a single question: “Are you bothered by loneliness?”. A dichotomous measure was established, classifying responses “Less often than once a month”, “Several or one time a month”, and “One time a week” as 0 (“Low”) and responses “Several times a week” and “Each day” as 1 (“High”). Psychosomatic complaints were assessed by asking participants about the frequency of experiencing stomach aches, headaches and difficulties falling asleep. Depression and anxiety symptoms were measured by the Patient Health Questionnaire-4 (PHQ-4) which is a brief screening scale for depression and anxiety (Kroenke et al., 2009). Register information on in-patient and out-patient care as well as on medication dispensing was drawn from the Swedish National Patients Register and the National Prescribed Drug Register, respectively. Information on gender was obtained from participants' personal identification numbers. Linear and logistic regression analyzes will be conducted (depending on the outcome studied). Crude models will include the main variables of interest only: loneliness measured at age 17-18 and mental health problems' indicators at age 19-20 and 20-21, from registers and from self-reports, respectively. In the analysis of the association between change in loneliness over time and mental health problems, only self-report data will be utilized, more specifically, information on change in loneliness from age 17-18 to age 20-21 and mental health problems at age 20-21. Adjusted models will additionally control for 1) baseline mental health problems and 2) sociodemographic characteristics. Adjustments will be made for sociodemographic factors that could be linked to both loneliness and various indicators of mental health problems. These factors include educational/employment status, living arrangements, parental education, parental country of birth, and parental mental health problems.

Results

We anticipate observing positive associations between loneliness and the mental health problems examined in this study. It is supposed that further adjustments for sociodemographic variables are unlikely to substantially affect the estimated relationships. The change in loneliness during this transition from late adolescence to young adulthood and its association with subsequent mental health will be discussed (it is expected that the change from low loneliness to high loneliness during this crucial period of life will show the most deleterious impact on mental health problems' indicators).

Complex care needs from a mental health perspective: A scoping review

Luna Van Suetendael (University of Antwerp), Kris Van den Broeck (University of Antwerp), Marianne Destoop (University of Antwerp), Geert Dom (University of Antwerp), Joris Michielsen (University of Antwerp)

Introduction

A well-known statistic is that one in four people will suffer from a mental health issue at one point in their lives. A group behind this statistic that is hard to define, to characterize and seemingly even harder to care for are those with so-called complex care needs. For many people with complex mental health care needs (CCN) there is a mental health care gap, resulting in unmet care needs, fragmented care, poor continuity and quality of care and health outcomes, service overuse, underuse or misuse.

This misuse of services is multi-directional: on the one hand we see that absence of needed social care can be linked to increased use of inappropriate medical care, on the other hand many people with CCN are not included in the mental health care system at all but remain in primary care or social welfare. At the same time, in-patient units report that patients with complex needs “get stuck” at the ward, because of a lack of appropriate and accessible housing and community services and family care providers also report feeling frustrated and

powerless, overburdened and family members at times feel stuck “between no help and coercion”. So, the issue of unmet needs in people with CCN is multifactorial and multisectoral and solutions will have to be addressed in the same way. To do this properly, it is first necessary to get a clear understanding of the concept of complex care needs. This scoping review aims to validate the concept of complex care needs from a mental health (care) perspective by mapping key characteristics described in literature.

Method

The scoping review will be conducted following the steps described in the Joanna Briggs Institute (JBI) Manual for Evidence Synthesis. Databases PubMed, Ovid, Cochrane and Social Services Abstracts will be searched. Grey literature will be searched for through Google Scholar. The scoping review is planned to be submitted in March 2024.

Results

Data will be reported descriptively. There will be a frequency count of characteristics mentioned in the literature, which will be reported in a table, complemented by a narrative description of the results. Preliminary results identify amongst others substance (ab)use, mental or physical disability, socio-economic vulnerability including poverty and housing insecurity and involvement with the criminal justice system as some of the complicating factors experienced by people with severe mental illness.

Discussion

It is clear that complexity arises more from the interplay between difficulties experienced, than from the simple sum of it. Intersectionality and complexity science could provide a framework for further interpretation of these results and for further research and practice development.

Conclusion

The findings of the scoping review will lead to a working definition of complex care needs from a mental health perspective and the development of a measurement tool. This will be used to study the care use (including overuse, underuse, misuse, interruptions in care use, ...) and to develop improved care programs for this population. Intersectionality and complexity science could provide a framework for this.

Reconsidering trauma in the nonnarrative (from a psychosocial ethnography of trauma-informed services)

Shoshana Lauter (London School of Economics and Political Science)

Introduction

Over the past three decades, the trauma concept has pervaded Western therapeutic culture, moving far beyond the warzone and into community mental healthcare to depict untold forms of suffering. But in the United Kingdom, the growing popularity of the trauma concept as an informer of care practices has received very little study. This study is particularly concerned with the concept’s function and effects amongst those who navigate mental health services most often and intimately. Individuals with complex and serious mental illnesses are adopting trauma-related discourses to reframe violence, crisis and precarity. The trauma-informed model is moreover proving to be a formidable voice as the broader field struggles to address the current mental health crisis. Understanding how service users narrate illness under its remit has never been more pressing (Kleinman 2012; Morgan and Kleinman 2010).

Methodology

The case study that will be presented is derived from ethnographic fieldwork for a doctoral thesis at two trauma-informed services in London: an NHS women's residential crisis house and a charity-based adult psychosis psychotherapy program. The eighteen-month study included participant-observation and semi-structured narrative interviews with service users. The fieldwork and subsequent analysis were framed by a psychosocial

methodology: an underutilized, psychoanalytically-inflected approach to questions that traditionally stay in the realm of sociological research. This methodology examines what insights the affective and unconscious, the internal world, can tell us about social experience; it reconceptualizes the service user as a complex and *defended* subject (Clarke 2006; Hollway and Jefferson 2013). Narratives that may be more chaotic, complex, or “harder to hear,” are seen as essential to the advancement of ethnographic research on subjectivity (Frank 1995: 97). In psychosocial research, the encounter between researcher and service user is reflexively considered as a shared meaning-making process.

Results

In this presentation, I provide a case study that includes an extract from a service user interview and a detailed description of a dinner conversation at one of the sites. Both involve service user reflections on iatrogenic harm from the psychiatric system. I will demonstrate through these examples how and where the trauma concept functions as an evasive descriptor, as part of the service users’ ‘nonnarrative’ — that which is unsaid, incomplete, inchoate (Kirmayer 2000). Using this case study, I argue that the trauma concept’s elusiveness has become a synecdochic tool (Marlovits 2020). It collapses service users’ knowledge of social suffering in with their serious mental illness. The stifling effects of this on service users’ senses of agency and perceptions of care are discussed.

Conclusion

The doctoral thesis applies a psychosocial methodology to explore how the trauma concept can both aid and obscure the true challenges of those with serious mental illness most closely tied to the mental healthcare system. After presenting a case study on trauma’s role in the service user’s ‘nonnarrative,’ I return briefly to the broader ideological implications of an unfettered use of the trauma concept (and related practices) in mental health services going forward.

Technology and Health, Regular Session – Chair: Veronica Moretti – Room K.103

We are molecularly in it! Endoptikon, circulation of health data and risks of online identity theft

Annalisa Plava (University of Bologna), Veronica Moretti (University of Bologna), Antonio Francesco Maturo (University of Bologna)

Introduction

Technological progress and the digitalization of data have provided criminals with new opportunities to obtain and misuse personal identity information. The emergence and spread of Online IDentity Theft (OIDT) is an example of this. Our sensitive data has a value providing a lot of information about habits, tastes, purchases. And increasingly, about physical and emotional states. Contemporary risks take on new characteristics and their effects are potentially unlimited. Cyberattacks on healthcare are on the rise by 74% worldwide. According to the report by Check Point cybersecurity company (2022) there were an average of 1463 cyberattacks per week in healthcare in 2022, an average of 209 attempts per day. These numbers make healthcare the first sector in terms of year-on-year percentage growth and the third in terms of overall cyberattacks.

As user-patients we directly generate this data and consent to it being stored by health professionals by interpreting and normalizing the online as a prosthesis of the offline. Data monitors us in extimacy and intimacy. In addition to the traditional forms of surveillance, control and self-discipline, today, we are willing to accept other more invasive but less perceptible surveillance forms in the field of health. In other words, we live in the Endoptikon system (Maturo, 2020) where control is under the skin, molecular. Being surveilled by sharing our medical data to professionals and related-tools to monitor our health state, therefore, is a risk we take even if not always aware of it.

In general, very little is known about the profile, needs and experiences of people whose personal identities information have been compromised or misused. But also of the risks and vulnerabilities that emerge from the data management and that impact on forms of victimization. European OI DT victims often do not report the crime, believing that the harm suffered is not significant enough or lacking adequate resources to counteract it. With the aim of analyzing the impact OI DT has in different European countries, but also to profile the victims, this proposal seeks to understand to which social factors online identity theft is linked.

Methodology

Given the sensitivity of the research topic and the need to investigate highly subjective factors but also to generalize fundamental experiential information, a qualitative methodology was chosen. The research involved all actors considered closely related to the issue of OI DT as victims, psychologists, lawyers, health/financial/digital forensics consultants, law enforcement agents. Regarding the methodology, we followed a mosaic approach and carried out 23 semi-structured interviews with experts and 43 structured interviews with victims.

The sampling logics were:

- (2) for semi-structured interviews with experts, focused on specific cases not statistically representative. The cases were chosen on the basis of their sociological significance (Cardano, 2020)
- (3) for the structured victims' interview, non-probabilistic, of convenience. In this case, the interviewees were partly self-selected within online communities identified by voluntary participation.

Results

Preliminary results highlight:

- (1) health data is highly attractive to criminals;
- (2) theft of health data creates a built in and often unconscious "fragility" on the users, who underestimate or do not consider the risk this may entail;
- (3) patient-users are constantly on the verge of vulnerability not because of their level of health literacy but of the security and recovery measures designed by healthcare companies.

Conclusion

This contribution, therefore, aims to open up reflection around the issue of online identity theft with a focus on that of health data. It is to critically analyze a problem that is submerged as it is underestimated in the activities of everyday life where we constantly relate to material, digital and/or virtual. However, it is a crucial problem. The consequences of health data breaches can be serious: in addition to the compromise of confidential information, such as patient records with reputational damage, they can lead to the delay or suspend even life-saving treatment.

Unfortunately, victims of identity theft in the medical field often lack rights and resources comparable to those available to deal with identity theft in the banking field. And the consequences can be, as it turns out, very serious. This study, therefore, wants to start a discussion and reflection around the issue with the aim of raising awareness among healthcare institutions and consequently support for user-patients constantly exposed to the risk but without real resources to prevent it.

Patient perspectives on the use of digital technologies and sensitive health data for AI driven medicine: lessons from Parkinson Disease

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Introduction

Parkinson Disease is a complex neurodegenerative disease affecting approximately 8.5 million people, with the number expected to rise to 12 million by 2040. The condition is characterized by a spectrum of combined motor and non-motor symptoms fluctuating over the course of the disease. As such it requires timely and accurate monitoring of treatment response, disease severity and progression. Recent advancements in digital technologies such as wearables and sensors coupled with AI (Artificial Intelligence) hold significant promise in addressing these needs in both clinical and research settings. By capturing precise and reliable longitudinal information regarding the daily functioning of individuals diagnosed with Parkinson's Disease (PD), these technologies can enable assessments of health trajectories, aid in clinical decision-making, and evaluate treatment effectiveness in clinical trials. Despite their increasing availability and the advantages of digital technologies, their successful implementation in healthcare and clinical trials will depend on patients' acceptance and engagement with these technologies. Numerous studies have now highlighted that different factors related to sociodemographic characteristics, digital literacy or privacy concerns and trust that can hinder their use. While research has demonstrated a high willingness and acceptance of digital medical devices in the general population, age, prior experience, and digital literacy were shown to be strong determinants of acceptance levels.

Objective

To understand patients' perspectives and concerns towards the use of DMDs and AI for the purpose of personalized medicine.

Methods

This is a cross-sectional study that was conducted as part of the EU-wide DIGIPD project, across France, Spain and Germany which aimed to validate digital biomarkers for enhanced personalized treatment of Parkinson's Disease. The study was conducted by multidisciplinary teams including neurodegenerative clinics in Paris, France and Erlangen, Germany as well as a Parkinson patient organization in Barcelona, Spain. The survey was divided into four main themes such as: sociodemographic information, use of digital devices and concerns, and patients' preferences. Additionally, we also ask for trust in AI for clinical decision support. The survey was tested for feasibility, to assess comprehension, and to make necessary adjustments. In the first step, we performed descriptive analysis of the sample characteristics and main variables related to the use DMDs, concerns and preferences. Next, for the categorical variables we used chi-squared and fisher exact tests to identify significant differences in DMD use, concerns, AI trust and preferences for data collection between different sociodemographic and disease duration groups, and between the different countries. Finally, we performed a logistic regression analysis to understand what sociodemographic and support factors (such as having instructions or receiving personalized feedback) predict the willingness to use DMDs and share health data for AI while controlling for the country effect.

Results

While we found an overall high willingness and acceptance to use DMDs and share personal health data, people with PD also have concerns related to their use. Most of the concerns about using DMDs were related to the time burden of using a device (11%) and the inability of handling the device even with support from others (9 %), which was particularly evident among the older population (63 % in those over 75 vs 13% in those under 65, $p=0.000$), and among those with higher PD duration ($p=0.51$)

In addition, we found that individuals with PD who are over the age of 75 were also less likely to be willing to use DMDs in the healthcare context (OR=0.31, 95% CI=0.11-0.83). Having instructions and feedback based on their obtained data increased the willingness to use DMDs almost 4-fold (OR=3.57, 95% CI= 1,44-8.89) and (OR=3,77, 95% CI= 1,01-14,12) respectively, although with a wide confidence interval mostly due to the sample size. The results also show that those within the older age categories are less likely to be willing to share their health data

for personalized care (OR=0.20, 95% CI= 0,06-0.63) for those between the age of 65 and 75, and (OR=0.11, 95% CI= 0,03-0.38) for those over the age of 75.

Conclusion

Our study underscores the importance of carefully considering patients' perspectives regarding the development and deployment of digital technologies for personalized care. The specific needs of older patients and patients with a more advanced disease stage need to be considered to increase adoption and meaningful engagement with DMDs as those are also the groups that could benefit the most from it. Further research needs to include the specific needs and perspectives of different migrant/ethnic groups, given the structural inequalities that these groups face in the healthcare system.

Evaluation of a multi-component digital self-management program for Long COVID-19: A qualitative study in Hong Kong

Leonard Ho (Chinese University of Hong Kong), Ming Hong Kwong (Chinese University of Hong Kong), Sam Ho Sum Yuen (Chinese University of Hong Kong), Pui Chee Hun (Chinese University of Hong Kong), Ka Wai Yuen (Chinese University of Hong Kong), Angus Siu Cheong Li (Chinese University of Hong Kong), Samuel Yeung Shan Wong (Chinese University of Hong Kong), Vincent Chi Ho Chung (Chinese University of Hong Kong)

Introduction

Long COVID-19 is a heterogeneous, multi-system, relapsing, and remitting condition that may affect patients recovered from COVID-19 regardless of the severity of their initial illness. Supported self-management is the guideline-recommended first-line intervention, but the content of such intervention varies. Based on the NHS Wales COVID Recovery App, we created a culturally relevant website and smartphone app, supplemented with a customer relationship management (CRM)-based mobile instant messaging system, to support interactive self-management of Long COVID-19 symptoms in the Hong Kong community. This study evaluated the attitudes, acceptance, and use of this multi-component digital platform among the users.

Methodology

Our platform was designed to provide users with free access to online materials (videos and textual instructions) to support their physical and psychological recovery from Long COVID-19 symptoms. We also communicated with users and relayed relevant health information via WhatsApp and Facebook Messenger on an interactive CRM system. Guided by the Meta-UTAUT (Unified Theory of Acceptance and Use of Technology) framework, we explored the views of users on the utilization of our platform via recorded semi-structured interviews after obtaining informed consent. We transcribed the interviews verbatim, conducted thematic analysis on the transcripts, and subsequently mapped the identified themes onto the seven domains of the Meta-UTAUT, namely performance expectancy, effort expectancy, social influence, facilitating conditions, perceived Information security, resistance to change, and perceived enjoyment.

Results

We interviewed 38 participants as of January 2024, of whom 44.7% were aged >60 years. The common facilitators for using the platform included: (1) the desire to acquire knowledge and skills for self-managing Long-COVID-19 symptoms; (2) the expectation of receiving information on referrals or being referred to on-site consultations; (3) the reputation of the host organization (i.e., a major medical school in Hong Kong). The common barriers included: (1) the lack of personalized content that takes into account the unique symptom profiles of the users; (2) the lack of bite-sized information that is readable on smartphones; and (3) the lack of referral services to public healthcare system. Performance expectancy, effort expectancy, and perceived enjoyment were the most relevant Meta-UTAUT domains that influenced the acceptance and use of our platform. Resistance to change did not play a significant role in affecting platform adoption, possibly because even older participants had had adequate exposure to digital devices. For older users, a simple but appealing user interface is essential to maximize acceptance. Of note, the use of CRM with broadcasted content and real-time interactions in the form

of instant messaging enabled two-way communications between users and service providers to build rapport, improving adherence to the self-management program.

Conclusions

Long COVID-19 patients tended to welcome receiving online self-management information, especially via WhatsApp or Facebook Messenger with interactive functions. Content providers should pay attention to the length of educational materials and how easily the patients follow the recommendations in daily life. Information should be tailored according to the interests and perhaps the symptom profiles of the users. Instant messaging is also recommended for providing support in a user-centered manner while gaining trust from the users.

Intersectional Disparities in Health and Illness, Regular Session - Chair: Sarah Van de Velde – Room K.201

An intersectional analysis of health inequalities across native and immigrant groups in Europe

Ana Maria Arias (Catholic University of Bolivia San Pablo), Paola Bedoya (Los Libertadores University), Marcela Losantos (Catholic University of Bolivia San Pablo)

Introduction

Intersectionality examines how social identities and systemic oppressions like gender, ethnicity, and class interconnect. It seeks to understand the multi-layered impacts of health inequalities, moving beyond individual attributes to broader societal structures. Traditionally a qualitative approach, recent quantitative advances have opened new avenues for exploring health disparities. This study leverages these methods to explore self-perceived health inequalities in Europe, focusing on intersections of gender, ethnic minority background, immigrant status, and feelings about household income.

Methodology

This study employs descriptive intersectional analysis using the Analysis of Individual Heterogeneity and Discriminatory Accuracy (AIHDA) approach. It used pooled data from seven waves of the European Social Survey (ESS, 2002-2018). It uses representative cross-sectional samples of all persons aged 15 and over (no upper age limit) residents in European countries. The study sample included 197,954 individuals from 27 European Union (EU) countries except Malta. The United Kingdom was included as, by 2018, it was still part of the EU. Individuals were aged between 18 and 65; this age group was selected because health outcomes might be highly influenced by aging and because working-age individuals were the focus of interest of the study. Natives - individuals born in the country- and immigrants from low and middle-income countries were included.

Variables

The outcome variable, self-reported health, is a crucial predictor of mortality, morbidity, and health service usage, reflecting individuals' physical and psychological health and overall well-being. This multidimensional indicator, valid across Europe, was assessed with the question: 'In general, how is your health?' with responses dichotomized into good and poor categories.

For AIHDA, independent variables included gender, ethnic minority status, and immigrant status. Household income feeling, dichotomized into comfortable living and financial difficulties, was a proxy for income. Age and survey year were adjusting variables. The study adopted McCall's intercategory approach and unlike traditional analyses of risk averages that consider a single social dimension, this study created intersectional groups by integrating the above-mentioned variables, thus leading to a multi-categorical variable with 16 strata, with highly educated majority ethnic group men as the reference group.

Statistical analysis

The statistical analysis in the study involved a series of logistic regression models to assess poor self-reported health (PSRH) using the AIHDA approach. Initially, Model 0 incorporated age and survey year. Subsequent models incrementally added gender, ethnic minority background, immigrant status, and household income feelings. In Model Va, the reference stratum was native males living comfortably, and in Model Vb, native women living comfortably. Finally, Model VI analyzed PSRH in women compared to men in each stratum (e.g., Native women living comfortably compared to native men living comfortably). Internal validation was performed using Bootstrap with 1000 repetitions. The Discriminatory Accuracy (DA) was assessed using the area under the receiver operator characteristic curve (AUC-ROC), with values ranging from 0.5 (no discrimination) to 1 (perfect discrimination). IBM SPSS Statistics was used for the analysis.

Results

In the study's results, Model IV highlighted increased risks of poor self-rated health (PSRH) among women, ethnic minorities, immigrants, and financially challenged individuals, with risks being 20%, 20%, 10%, and 2.2 times higher, respectively. Intercategorical comparisons (Models Va and Vb) showed that most groups had higher PSRH risks compared to native men and women living comfortably, except immigrant women and men living comfortably with ethnic minority backgrounds. Notably, native women with ethnic backgrounds and financial difficulties had the highest PSRH risks, with odds ratios (ORs) of 3.5 in Model Va and 3.2 in Model Vb. Immigrant women in similar conditions also showed elevated risks (ORs of 2.8 and 2.5 in Models Va and Vb, respectively). The discriminatory accuracy in Model IV reached an acceptable level (AU-ROC=0.70). In Model VI, women in most intersectional strata, except for the specified immigrant groups, had higher PSRH risks than their male counterparts, though lower than in Models Va and Vb.

Conclusion

The intersectional analysis of health inequalities using AIHDA demonstrated that intersections between the social categories of gender, migrant status, ethnicity, and income also form a clear and persistent social gradient for poor self-perceived health. At the most vulnerable end are women from ethnic minorities having financial difficulties, followed by their male counterparts. Additionally, women had a higher risk of poor self-perceived health compared to men across each pair of intersectional strata, even in the more advantaged strata.

“We were used like guinea pigs”: COVID-19 vaccine hesitancy among UK older ethnic minorities

Bridget Makande (Buckinghamshire New University)

Introduction

Vaccination is one of the public health tools pivotal to controlling and managing infectious diseases such as COVID-19. COVID-19 vaccination has therefore been central to the UK government's pandemic response. However, concerns have been raised about vaccine hesitancy among vulnerable populations, including older minority ethnic people, who have increased morbidity and mortality risk after contracting coronavirus. Minority ethnic adults had higher rates of COVID-19 vaccine hesitancy compared to white British adults.

Vaccine hesitancy is the delay in acceptance or refusal of vaccination despite vaccine services' availability. Vaccine hesitancy is complex and is attributed to multiple factors such as attitudes, beliefs, behaviors, and emotions. Understanding the dynamics of vaccine hesitancy is pivotal to tackling vaccine-preventable diseases, mitigating their impact, and promoting health. It is therefore important to gain insight into why older ethnic minority people in the UK are vaccine hesitant. Ethnic minorities are heterogeneous and constitute distinct social, cultural and economic profiles. Accordingly, they hold varying degrees of indecisiveness about vaccination. Furthermore, the reasoning behind their vaccine hesitancy can be very different in light of the intersection of their age, ethnicity, disability, socio-economic status, and other identity characteristics.

Methodology

This analysis is based on the findings of my qualitative study which explores the experiences of older ethnic minority people in the UK throughout and after the pandemic. One of the aims of this research is to acquire an improved understanding of the reasoning behind vaccine hesitancy among older minority ethnic people. The data is drawn from focus groups and individual interviews with older minority ethnic people, as well as individual interviews with community leaders.

This qualitative research centers intersectionality framework and risk theory to facilitate a nuanced analysis of the heightened risks that older minority ethnic people faced during the pandemic, and its aftermath. Intersectionality describes how various social identities such as race, ethnicity, age, gender, disability, comorbidity, and socio-economic status intersect and overlap to collectively oppress and marginalize (Crenshaw, 1989). Risk is the probability of hazards and insecurities induced and introduced by modernization itself. The conceptualizations of risk are also shaped simultaneously by socio-political processes and power structures (Olofsson *et al.*, 2014). These are the socio-economic and political stratifications which intersect to disadvantage the older minority ethnic people. Accordingly, this research project seeks to discuss older minority ethnic people's lived experiences, through considering how the interlocking systems of ageism, racism, ableism, and more impacted their lives.

Results

Conspiracy theories were a salient element of vaccine hesitancy for older minority ethnic people. They believed that the vaccine and the pandemic itself was a result of malevolent actions by powerful super rich groups. However, in contrast to conspiracy theories within the majority population, conspiracy theories within older minority ethnic communities were very closely tied to and fueled by pre-existing mistrust of government (health) services following their lived experiences of racism and discrimination. Their conspiratorial thinking and caution about the vaccine is empirically grounded, given the racialization of bodies and historical disregard for ethics in research involving minority ethnic people in the UK. An example is the 1969 Medical Research Council nutritional experiment in which South Asian women were exposed to radiation.

Their lived experiences of racism and discrimination also fed into gender-related conspiracy theories, with older minority ethnic people expressing fears that the vaccine constituted ingredients which would cause the sterilization of the younger generation to control ethnic minority population growth. Other reasons for vaccine hesitancy among older minority-ethnic people are tied to uncertainties about possible side effects given existing chronic conditions and age-related vulnerabilities. Vaccine hesitant older minority ethnic people trusted concoctions of traditional herbals to prevent infection than the vaccine.

Ethnic minority community leaders played a significant role in influencing their respective communities to get vaccinated. The use of community centers and Mosques as vaccination centers manned by in-group members as volunteers helped in building the trust of ethnic minority groups and convinced them to get vaccinated. Multigenerational living also played a role as younger family members living with the older people influenced the decision to take the COVID-19 vaccine or not. Behavior change theories which explain the dynamics of people's reaction to change also facilitate a better understanding of the older minority ethnic people's reaction to the transformed world and the slow acceptance of the new vaccine.

Conclusion

While vaccine hesitancy occurs across society, this study suggests that vaccine hesitancy among older minority ethnic communities was shaped and fed by their interlocking lived experiences of racism, ageism, and other forms of discrimination. This suggests that efforts to alleviate vaccine hesitancy within such communities must be cognizant of these underlying reasons and work to eradicate them. It also suggests that healthcare must be culturally sensitive so as to identify these fears.

The pull into wakefulness: How sociocultural categories intersect to shape sleep opportunity and sleep ability in Israel

Dana Zarhin (University of Haifa)

Introduction

Previous studies have reported the presence of sleep disparities among different social groups and have suggested potential explanations for these disparities. Factors associated with sleep disparities include race/ethnicity, socioeconomic status, and gender. Nonetheless, there are several gaps in the existing body of literature on this subject. First, the majority of prior research has predominantly relied on data from the United States, primarily focusing on Black/African Americans and white individuals. Consequently, there exists a critical need for research encompassing other racial and ethnic groups in different geographic locations. Further, the majority of previous studies have been quantitative and cross-sectional in nature, concentrating on correlations between individual variables while overlooking the potential impact of intersecting sociocultural identities on the experience and management of sleep. In order to gain a comprehensive understanding of this topic, empirical studies are necessary to illuminate the role of intersectionality and within-group variations. The current study addresses these gaps by focusing on the under-explored case of sleep in Israel and exploring how individuals' sociocultural identities intersect to influence the experience and management of sleep among midlife adults.

Methodology

This article draws on semi-structured interviews with 66 employed Israelis, aged 40-60, conducted between February 2020 and February 2022. Participants were selected using a purposeful sampling design that sought to include individuals with a wide range of sociodemographic backgrounds in terms of gender, ethnonationality, socioeconomic status, religion, and religiosity as well as the quality of sleep. The intention was not to create a statistically representative sample, but rather one driven by theoretical concerns.

Results

The findings demonstrate that intersections of gender, socioeconomic status, ethnonationality, religion, and religiosity prompt qualitatively different understandings, experiences, and management of sleep, in a way that affects both sleep opportunity and sleep ability. For example, many women in the sample explained that they could not go to sleep before they finished their household chores, indicating how this unpaid labor affected the duration of women's nighttime sleep, or in other words, their sleep opportunity. However, whereas most Jewish women napped during the day to add to their 24-hour sleep time, most Arab women reported having no time to nap. Arab women in the study recognized the importance of both nighttime sleep and daytime napping but felt that prioritizing sleep would require sacrificing other important responsibilities, such as family and household chores. They experienced time as more pressing and reported not having enough time for daytime napping due to their busy schedules. Sleep ability, or the amount of sleep a person is able to acquire, was affected by sociocultural factors as well. These include socioeconomic status [SES] and ethnonationality. Most respondents whose SES was medium-low or low recalled periods when concerns about their financial situation disrupted their sleep. Their concerns were so profound that they pulled respondents out of dormancy and into wakefulness, causing sleep deprivation, fatigue, and sleepiness throughout the day. Additionally, almost all respondents worried about their family members at times. These concerns were affected not only by personal issues, but also by the broader socio-political context: Several Arab participants expressed concerns about their family members' safety due to the growing violence in Arab neighborhoods and emphasized that it sometimes prevented them from falling or staying asleep. Jewish respondents recounted losing sleep over worries about their children serving in the Israeli Defense Forces.

Conclusion

This study contributes to the scholarly understanding of the social determinants of sleep. It emphasizes the need for a nuanced socioecological approach to understanding within-group variability in sleep experiences and management, providing insights into how intersections of gender, socioeconomic status, ethnonationality,

religion, and religiosity shape the lived experience and management of sleep. The results call for the design of tailored interventions that consider the sociocultural context, highlighting the importance of developing interventions that are sensitive to the diverse sociodemographic backgrounds of individuals and their unique experiences and needs related to sleep. That is, interventions should target the individual as both a biological and social being, as well as the social structure and context that shape individuals' sleep health. This is a challenging mission, but one with great potential to improve sleep health for all.

Intersectionality versus silo-formation in research on the social determinants of health inequalities

David Ingleby (University of Amsterdam)

Background

Work on the social determinants of health inequalities is carried out by research communities tending to specialize in one particular type of determinant or 'lens' (for example socio-economic differences, ethnicity and/or race, migrant status, sex and gender). By nature these communities are inward-looking: they are sometimes pejoratively described as 'silos'. Members prefer to collaborate with others in the same community, while communities compete with each other for scarce resources, claiming that 'their' variable is able to explain more variance than other people's.

By contrast, an intersectional approach emphasizes the importance of interactions between different determinants of health and the importance of studying these simultaneously. Its core assumption is that individuals are members of different social groups at the same time ('multiple identities'). Rather than main effects, it highlights the possibility that independent variables moderate each other's influence. Where such interactions exist, an intersectional approach will have more explanatory power than reductionist approaches that treat social groups as homogeneous.

Objectives

The presentation will first distinguish two meanings of the term 'intersectionality'. The classical version originated in the work of black feminists in the 1970's, who argued that traditional feminism was mainly developed by white middle-class intellectuals and overlooked the specific forms of oppression suffered by women of color. This concept of intersectionality was first elaborated by the legal scholar Kimberlé Crenshaw in 1989, although it did not gain widespread influence until some 20 years later. Since then, the use of the term by feminist researchers has grown exponentially, the volume of publications doubling approximately every 3 years. In this literature 'intersectionality' is identified not only with an emphasis on multiple identities, gender and oppression, but also with a methodological paradigm prioritizing qualitative methods, participatory action research and reflexivity.

As the term became more widely known, however, it was also adopted by researchers who interpreted it far more broadly. While retaining the stress on multiple identities, a much wider range of determinants of inequality than race and gender was examined, while not all the methodological imperatives of the 'classical' paradigm were adhered to. According to the publications database Scopus, more than half of the publications including 'intersectionality' or 'intersectional' in their title, keywords or abstracts nowhere mention the terms 'feminist' or 'feminism'. This work often uses multivariate analysis, a technique which considers different determinants simultaneously and reveals how they can moderate each other's effects. This approach has been a standard tool of epidemiological analysis since the time that computers became widely accessible.

This presentation will present the results of ongoing bibliometric analyses using Scopus, mapping the development of research on four major determinants of health inequalities or 'lenses': socio-economic differences, ethnicity and/or race, and migrant status (distinguishing between refugees and other migrants). Research on sex and gender differences is not treated as a separate issue, as it figures in all four approaches.

Attention will be paid to the historical, geographical and methodological trends which influence the global distribution of research on these factors.

As a case study, the presentation will finally illustrate how an intersectional approach to the joint influence of migrant status and socio-economic factors can be modelled, using the 'policy framework for analysis' (PFA) that was developed for Working Party 7 on Migration in the Joint Action on Health Equity in Europe (JAHEE). This project of the EU Health Program was carried out by 24 Member States between 2014 and 2020.

The research communities concerned with these two 'lenses' have many of the characteristics of silos. All too often, the relation between them is treated as competitive: in particular, inside the socio-economic silo it is often argued that many effects attributed to migrant status 'really' result from socio-economic position (SEP). This reductionist tactic ignores the fact that in multivariate analysis, a confounder may not lie on the causal path between independent and dependent variables, whereas migrant status often limits the SEP that a migrant can achieve.

WP7 developed an intersectional model showing how both determinants interact to undermine health. Sometimes migrant status has a direct, i.e. unmediated effect – for example, through discrimination of various kinds, or because of the 'dirty, difficult and dangerous' work that migrants are often obliged to do. Inadequate enforcement of labor legislation, resulting in exploitation, generates widespread health risks for migrants. However, migrant status can also act as a *moderator*, affecting migrants' exposure or vulnerability to health risks potentially affecting all workers. Migrants lacking an adequate safety-net of benefits to safeguard against the effects of unemployment are exposed to greater health risks than nationals. Other effects, however, are indirect and mediated by SEP: they result from the many obstacles to social mobility that face migrants. The resulting theoretical model is proposed as a way of combining the strengths of research on both SEP and migrant status.

Inequalities in mental health changes before and during the COVID-19 pandemic in the Netherlands: Examining the combined influences of educational level, income level, gender, and age through an intersectional lens

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Introduction

This study investigates how socioeconomic factors, gender, and age intersect to shape mental health inequalities before and during the COVID-19 pandemic in the Netherlands. Some anticipated that the pandemic would act as "the great equalizer" by affecting people across different societal positions similarly, whereas others hypothesized that the pandemic would disproportionately affect vulnerable groups, exacerbating existing mental health inequalities and creating new ones. National statistics revealed small overall declines in mental health in the Netherlands during the pandemic, and mental health inequalities have been found across socioeconomic factors, age, and gender. However, the majority of studies examined these inequalities in isolation, by controlling for factors such as age and gender, rather than studying how people's unique, intersecting combinations of advantages and disadvantages have shaped their mental health. This study explores intersectional inequalities in changes in mental health before (2014) and during COVID-19 (2021) in the Netherlands based on educational level, income level, gender, and age. Understanding how mental health status has changed, and perhaps changed differently, for different populations is essential to recognizing patterns of need and excess burden, the first step toward addressing collective trauma and preparing for responses to future crises.

Methods

This study uses longitudinal GLOBE (Dutch acronym for "Health and Living Conditions of the Population of Eindhoven and surroundings") data, collected in the Netherlands. Waves of 2014 and 2021 were used to explore

intersectional inequalities in mental health pre- (2014) and during (2021) COVID-19. Participants were assigned to one of 54 social strata based on their unique combination of self-reported educational level, income level, age, and gender. Mental health outcomes were measured using the Mental Health Inventory-5. Data of 1157 participants with complete data for both 2014 and 2021 on the variables used was included, and 53 of the 54 potential social strata were represented in our data, of which 45 social strata contained sufficient participants for our analysis. We applied Multilevel Analysis of Individual Heterogeneity and Discriminatory Accuracy (MAIHDA) to explore intersectional inequalities in mental health in 2014, 2021, and in mental health changes between 2014 and 2021. MAIHDA places individuals (level 1) in social strata (level 2) based on their shared characteristics in terms of educational level, income level, age, and gender. Discriminatory accuracy of the different social strata was used to identify intersectional inequalities in mental health.

Results

For the sample overall, mental health decreased only slightly between waves, with a 1 percentage point drop between 2014 and 2021. However, preliminary results show that there was significant heterogeneity of change across intersectional strata. In particular, in 2014, those aged 65 and older experienced mental health advantages, but between 2014 and 2021, older strata tended to experience large mental health setbacks, dissolving their previous mental health advantage. Younger populations fared differently, with most strata aged <40 years experiencing small declines in mental health. Strata between ages 40 and 65 had mixed trends, with some slightly increasing and others decreasing in mental health scores. Inequalities in mental health based on income persisted between waves, but no significant educational inequalities were found. Females experienced persistent disadvantages in their mental health, however, this gender inequality slightly flattened between 2014 and 2021.

Conclusions

Observed inequalities in mental health in 2014, 2021, and inequalities in the change between waves were mainly describable with additive effects of income, gender, and age, rather than interaction effects. This implies that mechanisms of disadvantage such as income, age, and gender, seem to operate rather distinctively in their influence on mental health among the Dutch adult population. Inequalities were identified based on having a lower income and being female, in line with previous literature. However, whereas previous literature suggested that older populations had more mental resilience to cope with the crisis, our analyzes revealed substantial mental health declines among those aged 65 and older. In future public health crises, more effort needs to be taken to protect the mental well-being of the full population, with specific attention to protecting the elderly. Despite income support and additional financial COVID support issued by the Dutch government, income inequalities in mental health remained relatively stable between 2014 and 2021. Since the government has started recollecting COVID loans as of 2022, income inequalities may have further widened since then, which could have negative consequences for (intersectional) mental health inequalities. This should be examined in future research.

Life Course Perspectives on Health, Thematic Session – Chair: Bram Vanhoutte – Room K.202

Ageing fast and slow: A longitudinal examination of the gap between subjective and chronological age

Bram Vanhoutte (Free University of Brussels), Akinochi El Mouksitou (Free University of Brussels)

Background

Chronological age, or the number of years elapsed since birth, is one of the key structural determinants to one's identity, perhaps only second to gender. Age is equally internalized as a mental state, a self-description of one's age, independent of chronological age, as subjective age. It is a longstanding fact that subjective age is strongly

influenced by health status. Few studies have explored this relation with longitudinal data, distinguishing age from cohort effects.

Objectives

Our aim is threefold: 1) To examine the longitudinal evolution of the age differential between subjective and chronological age 2) To examine how functional health issues, both seen as limitations in physical and mental function, affect the evolution of this age differential, and 3) What the impact is of onset of a functional limitation on the age differential.

Methods

This study analyzes data from four waves of the English Longitudinal Study on Ageing (ELSA), making use of 36,646 observations of 14,601 participants. We investigate the longitudinal evolution over age of the difference between the chronological age and the subjective age, conditional on cohort, using the age vector specification of random intercept mixed models. We subsequently examine the age cohort trajectories, the age cohort trajectories by functional limitations group, as well as the influence of gender, educational level, and marital status using a fixed effects model.

Results

Participants felt on average about nine years younger than their actual age. Subjective ageing happens about a third slower than objective ageing on average. Later born cohorts feel younger than earlier born cohorts at a given age. The difference between chronological age and subjective age is about 8 years between those with functional health limitations, but onset of such functional limitations only decrease the gap with about one to three years.

Conclusion

Functional health status influences subjective age even after adjusting for socio-demographic variables. While there is a marked decrease of the gap between objective and chronological age with the onset of a functional health limitations, most of the difference is due to selection into losing functional health, rather than functional health loss itself.

Cumulative health effects of work precarity and unemployment. Longitudinal analysis of German national panel data.

Malgorzata (Gosia) Mikucka (Mannheim University), Oliver Arránz Becker (Martin-Luther-University Halle-Wittenberg), Christof Wolf (GESIS - Leibniz Institute for the Social Sciences)

Introduction

Work precarity refers to the unsettling insecurity in employment, encompassing various dimensions, such as job insecurity, poor working conditions, limited workplace protection, or dependence on low wages (Kalleberg, 2018). Similar insecurity arises from unemployment, typically associated with economic deprivation and the loss of latent benefits of employment (Jahoda, 1982). This paper refers to "adverse employment situations" as an umbrella term comprising work precarity and unemployment.

Tomba et al. (2007) proposed three main causal pathways between adverse employment and health: stress, physical exposure, and economic deprivation. In line with the risk accumulation model, it is plausible that the health consequences resulting from these risk factors accumulate over the course of one's life. (Ben-Shlomo, 2002). This implies that not only the current employment situation but also the number or duration of past exposures to adverse employment may shape people's health. However, among the many studies analyzing the link between (some aspects of) adverse employment and health, only a handful conceptualized health formation as a cumulative process (Fletcher, Sindelar, & Yamaguchi, 2011; Schunck, Sauer, & Valet, 2015; Stauder, 2019; Wickrama, Surjadi, Lorenz, & Elder, 2008). Even fewer analyzes relied on data with a long observation window

and multiple time points to analyze this dynamic (Benach et al., 2014; Willson, Shuey, & Elder, Jr., 2007). This paper contributes to the debate by conceptualizing health formation as a cumulative process and testing the hypothesis that, above and beyond the current adverse employment, also past experiences of adverse employment predict an individual's health.

Methodology

We used data from the GSOEP (version 35), a large national panel study of private households in Germany, conducted yearly since 1984 (Goebel et al., 2019; GSOEP, 2019). The GSOEP offers unique data to study cumulative health formation, as it monitors respondents' health and employment for up to 17 years.

As outcomes, we consider measures of physical and mental health (recorded biennially 2002–2018) measured by the SF-12 scale (Andersen, Mühlbacher, Nübling, Schupp, & Wagner, 2007; Ware Jr, Kosinski, & Keller, 1996). The main predictors of interest are indicators of respondents' adverse employment. The instantaneous effects of adverse employment represent health shifts that accompany entering and exiting adverse employment. Additionally, cumulative exposure variables model the cumulative effects, allowing that each additional year in adverse employment has health consequences which persist after leaving adverse employment.

The analysis uses fixed effects (FE) regression to estimate health changes associated with moving between adverse and non-adverse employment, controlling for all time-invariant differences among individuals (e.g., baseline health, personality traits, education, etc.; see: Brüderl & Ludwig, 2014). By including an interaction between age and education and gender we relaxed the "parallel trends" assumption (Ludwig & Brüderl, 2018) allowing age slopes to differ across social categories.

Results

Our results showed that unemployment, subjective job security, and income dissatisfaction correlated with worse health. Statistically significant were the instantaneous effects, meaning that health worsened in the periods of adverse employment, as well as the cumulative effects, indicating that health consequences of adverse employment situations persisted over time and cumulated to shape individuals' health (cumulative effect of unemployment was significant for physical health only). The sizes of instantaneous effects were relatively large, corresponding to accumulation occurring over a period of 5.5-13 years, depending on precarity measure and health dimension.

For other measures, such as overemployment or economic inactivity, the immediate and accumulated effects were not aligned. The health effects of these measures did not accumulate over time, suggesting a complex pattern of relationship between adverse employment and health.

Conclusions

The concept of risk accumulation is established in the literature, but few studies have explored the cumulative effects of adverse employment. We addressed this gap by analyzing how 17 years of work precarity experiences impact the health of individuals. Our study is among the first to estimate the long-term cumulative effects of adverse employment on health.

Adverse employment histories, later stress at work, and Allostatic Load

Morten Wahrendorf (University of Düsseldorf), Johannes Siegrist (University of Düsseldorf)

Abstract

Adverse employment histories have been associated with allostatic load (AL), and exposure to chronic stress at work and related physiological stress responses have been proposed as a socio-biological pathway. This presentation uses baseline data from the French population-based CONSTANCES study, with data from 44,189 participants, and examines the direct and indirect effects (via subsequent work stress) of previous adverse

employment history on AL. Adverse work histories are assessed retrospectively in terms of precarious, discontinued and disadvantaged work histories between the ages of 25 and 45. Work stress and AL are measured at baseline in terms of effort-reward imbalance, and we use a composite allostatic load score based on 10 biomarkers. We conduct causal mediation analyses based on a potential outcome approach (adjusted for age, educational attainment, partnership situation and sex) to decompose direct and indirect effects (via stress at work) of employment history on AL. Preliminary results suggest that both work stress and an adverse employment history are associated with higher AL, and that only a small part of the effect of employment history is due to mediation by work stress. This is consistent with a risk accumulation model in which both history and job stress are independently associated with higher AL.

Understanding resilience in ageing in Europe: Mapping trajectories of wellbeing after functional disability

Thibault Köhler (Free University of Brussels), Bram Vanhoutte (Free University of Brussels)

Introduction

Can we age well when our health has been compromised? Successful ageing seen as an old age free from disability and disease, but with high levels of cognitive and physical function suggests this is impossible (Rowe & Kahn, 1997). Remarkably, most people feel they manage relatively well in later life, despite health challenges (Bowling and Dieppe, 2005). According to the controversial idea of a hedonic treadmill (Brickman & Campbell, 1971), people's well-being returns to a set-point after experiencing either positive or negative shocks. In the specific context of functional disability, studies differ on the degree of adaptation following this event. This study aims to contribute nuances to this debate in two ways. First by adopting a multidimensional approach to wellbeing in later life (Vanhoutte, 2014), differentiating between affective, cognitive, and eudemonic wellbeing. Second, by examining how wellbeing trajectories are influenced by temporary functional disability, distinguishing between persistent and transient cases.

Methods

We use data from waves 4 to 8 of the Survey of Health, Ageing and Retirement in Europe (SHARE). Functional disability is defined as the transition from having no limitations to at least one limitation in activities of daily living (ADL) corresponding to more than more than 3900 transitions from 12 country. All individuals' trajectories were aligned on the point of transition, creating a time to/from disability metric, with standardized measures of wellbeing to allow them to be compared. We used spline growth models separately for each wellbeing measure (using CES-D, life satisfaction and CASP) to examine non-linear trajectories. In a subsequent step, Growth Mixture Modeling (GMM) was used to move beyond describing a single overall trajectory of change over time, allowing for the identification of distinct sub-groups within the data. Following this, multinomial logistic regression was then used to identify drivers influencing specific responses, examining how various background characteristics are associated with different forms of coping.

Results

We observed a significant decline in all three measures of wellbeing at the onset of functional disability, with life satisfaction less affected (Standardized mean differences = -0.12) than quality of life (-0.19) and depression (-0.24). Regarding the influence of temporary, individuals with transient functional disability exhibited a more resilient response during the transition (except for depression) and quickly return to their initial level of wellbeing. Conversely, people with persistent cases experience a more pronounced impact during the transition and a significant and lasting decline. Regarding Growth mixture modelling, we find 4 different types of reactions to a health shock (bouncing back, carrying on, delayed negative impact or immediate negative impact) based on earlier work (G. A. Bonanno et al., 2002). Additionally, we uncover diverse associations between resilience and social position. Specifically, younger, wealthier, and more advantaged women with a lot of social support, are likely to 'bounce back' more often. In parallel, younger, wealthier, and more advantaged men are expected to

'carry on' and individuals who are economically disadvantaged, socially isolated, and either single or widowed may exhibit either delayed or immediate negative impact.

Conclusion

Our findings highlight the significant impact that functional disability can have on wellbeing, revealing distinct patterns across various dimensions. Persistent functional disability represents a turning point for the wellbeing of older people, with only life satisfaction showing signs of adaptation. More optimistically, our study shows that functional disability is often a transient challenge, and in such instances older people tend to regain their previous level of wellbeing.

Studying (Non-)Participation in Health Research: Experiences, Research and Theories, **Thematic Session – Chair: Minna Laiti – Room K.203**

Counteracting the spread of antimicrobial resistance: building common knowledge in a One Health perspective

Francesca Zaltron (University of Eastern Piedmont), Anna Rosa Favretto (University of Turin), Stefania Fucci (University of Parma), Paola Tomao (INAIL), Nicoletta Vonesch (INAIL), Alessandro Manelli (University of Turin)

The concept of 'One Health' (OH), which has emerged since the first decade of the 21st century (Rüegg et al., 2018; WCS, 2004), recognizes the existence of a close connection between the health of people, animals and the environment. OH is not only a research paradigm, but also and above all a paradigm of action, which promotes health by leveraging an interdisciplinary approach, aiming at integration between professionals, researchers and experts in different fields of study, levels of government, public policy sectors, beneficiaries and stakeholders (Balduzzi & Favretto, 2018, 2021). In the face of systemic emergencies, including that of the growing antimicrobial resistance, OH calls for collaboration both between scientists belonging to different, traditionally separate scientific-disciplinary fields (biologists, physicians, veterinarians, but also scholars in the human and social sciences), and between different kinds of knowledge: expert and lay knowledge.

This perspective will be used in order to analyze the phenomenon of antimicrobial resistance, now considered an issue of global relevance with regard to the protection of human health. Among the causes linked to this phenomenon is the overuse of antibiotics in both human and veterinary settings, including the food chain livestock sector (FAO, 2016).

In the zootechnical field, the Italian Ministry of Health has recently issued some guidelines (2012, 2016), which contain provisions for veterinary personnel and recommendations for breeders oriented towards responsible use of antibiotics and herds management.

Some authors (Buller et al., 2016; Kramer et al., 2017) have found a lack of efficacy of such measures and communication methods, relying on two critical aspects: the unidirectional nature of information from expert knowledge to livestock operators (a top-down manner) and the fact that it is based on a supposed virtuous automatism between among the provision of information, the increase of awareness and the adoption of good practices.

The aforementioned unidirectionality has long been subject to criticism and revision through the adoption of participatory pathways (Brown, 1992; Popay & Williams, 1996). They are pathways based on the necessary integration of knowledge (Hamilton, 2018), so as to convey information, knowledge and good practices aimed at encompassing the different interests, knowledge and skills of all the actors acting in the specific areas of healthcare competence. These theoretical-methodological and operational transformations do not yet seem to have largely involved the zootechnical sector.

This contribution will particularly consider the analysis of the elements that make up the ‘practical knowledge’ of breeders on the phenomenon of antimicrobial resistance and the relationship between this knowledge and the ‘expert knowledge’, probing the possibility of setting up ‘participatory’ pathways of scientific knowledge construction for livestock breeders and workers in the livestock sector.

‘Practical knowledge’, as a source of orientation for carrying out of the working activities, is intended here as the complex set of elements (representations concerning the phenomenon, daily farming practices, meanings attributed to these practices, sources and ways deemed trustworthy through which the contents of the regulations and measures oriented towards health protection are acquired, etc.) called upon to confront, and possibly transform, regulatory prescriptions and scientific knowledge.

Our contribution will present some results of the interdisciplinary research-intervention “Realisation of a network aimed at communicating and reducing the risk of spreading antimicrobial resistance in exposed workers”, financed by INAIL (Italian Labour Accident Insurance Institute) and concerning the individuation of good practices to reduce the exposure of workers in the pig and poultry sectors of intensive livestock farms in two different regions in the northern of Italy (Emilia Romagna and Lombardy) to antimicrobial-resistant agents. In the first phase of the research, semi-structured interviews were realized with farmer and veterinary aimed at collecting complex narratives of working practices and scientific knowledge on procedure to contrast antimicrobial-resistance. Then, in the second phase, data from the interviews were used in structured arenas in order to draw up participatory guidelines with farmers and veterinarians.

In particular we will present: 1) some reflections on breeders’ representations of the phenomenon and their difficulties in applying the regulations and recommendations of expert knowledge; 2) the ways in which breeders and workers integrate new knowledge and needs to regulatory compliance into their ‘practical knowledge’, with particular attention to contextual constraints; 3) the good practices emerged during the structured arenas by the integration of ‘expert knowledge’ and ‘practical knowledge’ to counter the spread of antimicrobial resistance in the livestock sector.

Strengthening social inclusion in young people’s mental health: Experiences of Finnish LGBTIQ+ young people

Minna Laiti (University of Helsinki), Kaisa Marttila (University of Helsinki), Satu Venäläinen (University of Eastern-Finland), Ainara Ossa Rissanen (University of Helsinki), Päivi Berg (University of Helsinki)

Introduction

The prevalence of mental health problems among young people has increased drastically, in Finland as well as other Western countries. The key challenges for Finnish mental health services are an increased demand for low-threshold access to services, a need for efficient use of existing resources for high-quality care, and a lack for professionals who can provide psychosocial interventions in primary care. Simultaneously, it is known that young people belonging to sexual and gender minorities (LGBTIQ+) are vulnerable to certain health disparities, such as a higher risk for depression, anxiety, and suicidal ideation. Literature has also recognized that LGBTIQ+ people have unequal access to healthcare services, and that the services often fail to meet their unique needs. Previous health research has also shown a lack among professionals in knowledge and skills that are needed to provide effective and inclusive care for LGBTIQ+ populations. Therefore, there is a need to for knowledge on how young LGBTIQ+ people experience the current situation of Finnish mental health services, and their perceptions on how to support social inclusion and equality in mental health services.

Methodology

Our research project “Inclusion and (in)equalities in psychosocial interventions targeted at young people” produces research evidence on how social inclusion and equality of young people are achieved in mental health services. We explore young people’s views on challenges in the current psychosocial interventions regarding

social inclusion, and how the current interventions and mental health services manage to support the mental health of diverse young people. The research project draws on a multidisciplinary approach with a focus on gender and intersecting identities, combining insights from disciplines such as youth research, social psychology, and gender studies.

As part of our research project, we have conducted focus group interviews with young people belonging into different minority groups. Our aim was to enhance the active involvement of minority groups in research and evaluation of psychosocial interventions and mental health services. We also aim to create an understanding of elements that influence social inclusion, equality, motivation, and adherence to interventions. The results support the development of mental health services' capacity to meet the needs of young people belonging to different minority groups, and thus provide tools for improving equality in mental health and wellbeing.

In our presentation, we describe the preliminary results of a focus group study with Finnish LGBTIQ+ young people. A total of four (N=4) focus group interviews with 13 LGBTIQ+ young people were conducted between Autumn 2023 and Spring 2024. Our preliminary findings are based on an ongoing reflexive thematic analysis.

Results

According to the preliminary results, LGBTIQ+ young people perceived that mental health services were unequal, and that the possibilities for young people to get help for mental health problems were not the same for all. The intersectional approach was desired in the mental health services and interventions, as LGBTIQ+ young people considered it as an important aspect for achieving social inclusion and equality. The participants worried about how mental health professionals' possible negative attitudes towards LGBTIQ+ people may affect receiving help, and they expressed uncertainty about how inclusive mental health services are. Furthermore, they saw that the preparedness of mental health professionals to provide care with a sensitivity to LGBTIQ+- specific issues was inadequate, especially regarding gender diversity. However, LGBTIQ+ young people expressed that participating in focus groups offered valuable peer support and experiences of empowerment with mental health topics. Peer and community support offered them ways to reflect their experiences as a minority group, and this could empower them to have a sense of belonging.

Conclusions

The focus group interviews with LGBTIQ+ young people indicate that the current Finnish mental health services do not adequately recognize intersectionality as a part of mental health. Moreover, LGBTIQ+ young people experience concern about health professionals' capacity to act inclusively and acceptingly towards sexual and gender diversity. Their experiences indicate that professionals especially lack knowledge on gender diversity. The results provide further support for the findings of previous health research and highlight the fact that mental healthcare systems need to be further developed to address the unique needs and challenges faced by young people with intersecting identities, in order to enhance equality and equity in mental health.

The use of Machine Translation for outreach and health communication in Epidemiology and Public Health (Scoping Review)

Paula Sofia Herrera-Espejel (Leibniz Institute for Prevention Research and Epidemiology), Stefan Rach (Leibniz Institute for Prevention Research and Epidemiology)

Introduction

The languages chosen in public health (PH) materials affect how different population subgroups engage with the presented information. For instance, this is the case for population-based study invitations, where nonresponse may become tied to the language abilities of addressees. Should the recruited samples fail to represent certain segments, derived study estimates might become biased, thereby limiting the generalizability of their results. As a consequence, linguistically diverse subgroups, often termed "hard-to-reach", are challenged by two effects: the medical and health knowledge is less accessible to them, while at the same time, it might not adequately

cater to their particular needs. Machine translation (MT) tools have been reported to be useful for overcoming language barriers in clinical settings. How does MT fare in PH research? Our scoping review (ScR) aims to systematically investigate how MT is currently used in the fields of PH and epidemiology, particularly for population-based recruitment methods.

Methodology

We conducted the ScR in accordance with the JBI Manual for Evidence Synthesis and the PRISMA-ScR checklist. We searched PubMed, PubMed Central, Scopus, ACM Digital Library, and IEEE Xplore. For each selected article, we extracted its bibliographic characteristics, as well as content on PH information exchange scenarios, corresponding study designs, and principal findings concerning technical, socioeconomic, or ethico-legal readiness levels of MT technology. We assessed the information exchange scenarios using a settings approach to health promotion and classified the study designs according to the World Health Organization (WHO) monitoring and evaluation framework. Based on a manual sentiment analysis, we detected the tonality of selected conclusions, and classified them as positive, neutral or negative.

Results

Our search yielded a total of 7186 articles identified of which 46 (0.64%) were included in the review. Selected articles were published between 2009 and 2023 as either conference articles (12/46, 26%) or articles in traditional journals (34/46, 74%). The most frequent transmitters were PH professionals (21/46, 46%) using MT to translate different types of documents (e.g., promotional material or educational resources), which were mainly addressed to target audiences offline and seeking information online. Secondly, clinical and hospital staff (e.g., nurses) (15/46, 32%) were reported to use MT to create simplified medical information (e.g., prescriptions or emergency handouts). In a third and fourth case, the literature discussed MT's usage by international and national organizations (e.g., WHO or FDA) (8/46, 17%) for translating global health guidelines and its testing by developers (2/46, 4%).

Regarding study designs, nearly three-quarters (34/46, 74%) of the articles provided technical assessments of MT from one language (typically English) to a few others (mostly, Spanish, Chinese, or French). Most of the experiments in these studies (27/34, 79%) recruited participants among PH professionals and certified translators with high proficiency in target and source languages, or some experience with PH vocabulary. Only a few (12/46, 26%) explored end-user attitudes (mainly of PH employees), whereas none examined the ethico-legal implications of MT quality, efficiency, or equitable access across different languages on possible information disparities. The majority (36/46, 78%) of the articles under review drew conclusions regarding the technical readiness of MT, nearly half (21/46, 46%) its socioeconomic readiness, and more than a quarter (13/46, 28%) discussed its ethico-legal readiness. A total of 70 conclusive statements were identified within the 46 articles. Overall, we found out that one fifth of the statements (16/70, 23%) within the articles expressed optimism about the use of MT for PH purposes, while another fifth was pessimistic (16/70, 23%), and the remainder (38/70, 54%) presented inconclusive results. In general, some studies confirmed the PH workers' enthusiasm for adopting MT to improve cost-effectiveness and increase equitable access to information, while most cautioned against the technology's use without human editing.

Conclusion

Evidence from the ScR suggests that MT as a tool for engaging specific subgroups is still in its early stages. Overall, we observed that, out of the 46 selected studies, the bulk of existing research predominantly centers around the technical readiness of MT and presents mixed results. Most studies focus on translations from the language of PH staff or researchers to target languages used in the anglosphere (e.g. USA). In fact, most experiments interviewed professionals, limiting study insights to expert perspectives. Moreover, the literature revolves around the use of MT for one-way communication scenarios that do not warrant a response from addressees (e.g. participation consent). As such, there is a lack of research regarding how machine-translated information is received across different population segments or might be used to enhance participation in PH research.

Inequalities in children's participation in environmental health research: An intersectional approach

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Introduction

The *HesiBerdea* project aims to analyze the impact of placing vegetation in a schoolyard on the yard's pollution and the perception of preschool and primary students. To collect data from the children, it was necessary to obtain informed consent from the families. This communication intends to analyze the informed consent process to determine if non-response had differential behavior according to children's origin and gender.

Methods

The process to encourage student participation had several stages. Firstly, families were informed about the project during the start-of-year meetings. Also, a few days before delivering the consents to the families, a video about the project was distributed. The consents were handed out by the tutors to the students, who were to return them signed. Furthermore, subsequent work was done with the families to increase participation among those who had not submitted the consent in the first round. The study will present the evaluation of the process in terms of participation percentages by origin and gender, as well as a reflection on the reasons for non-participation of people in more disadvantaged situations, based on the work done with these families.

Results

Although the results are still in progress, a higher non-participation of the most disadvantaged families in the first round has been shown. While participation among native families was 91%, it dropped to 31% among families of foreign origin. After initial work with the non-participating families, participation from families of foreign origin increased by 17%. Lack of understanding of the study and the consent form, as well as lesser importance given to the studied factors by foreign families, were some of the reasons that emerged strongly in the preliminary results of the work with non-participating families. The communication will show more results on participation inequalities and their reasons.

Conclusions

This study not only highlights the importance for the research itself (response rate) of considering differential non-participation in health research based on the ethnic and economic background of families, but it also underscores how intersectional factors can influence this phenomenon. Our findings suggest that recruitment and consent strategies in health research should be consciously inclusive and sensitive to these differences. These strategies prevent methodologically biased research that does not reflect the diversity of our communities. This intersectional approach not only addresses the existing inequalities in research participation but also is essential to develop truly inclusive and effective health policies and practices in improving the health and well-being of everyone.

5 July: 15:40 – 16:30

Closing Ceremony – Room K.001

Awarding the Activism Prize and Excellence Prize