Social support for informal caregivers of community-dwelling frail elderly

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Social support for informal caregivers of community-dwelling frail elderly

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Chapter 1
Introduction

Introduction

Taking care of ageing relatives is as old as humanity [1]. Yet due to demographic changes in the modern-day society, the concept knows a growing interest in policy and research in the recent years [2]. The ageing of the population, the increase of frail older people with complex care needs and staff shortages in health care put a pressure on governments and long-term care providers to search for and implement affordable alternatives for residential care for this growing group of frail elderly [3]. The general preference to postpone or avoid residential care also means that the informal caregiver plays a more prominent role in the daily care for the older person at home [4, 5]. Sociodemographic evolutions with more women building a professional career, later retirement, smaller families, families living further away from each other, may limit the availability of informal caregivers and put a pressure on those who do take on the role of informal caregiver [6, 7]. While many informal caregivers find satisfaction in providing care for a loved one, it can also be challenging and may cause the informal caregiver to experience physical and mental health problems, financial problems and social isolation. A negative appraisal of the caregiving situation by the informal caregiver can lead to among others fatigue and stress.

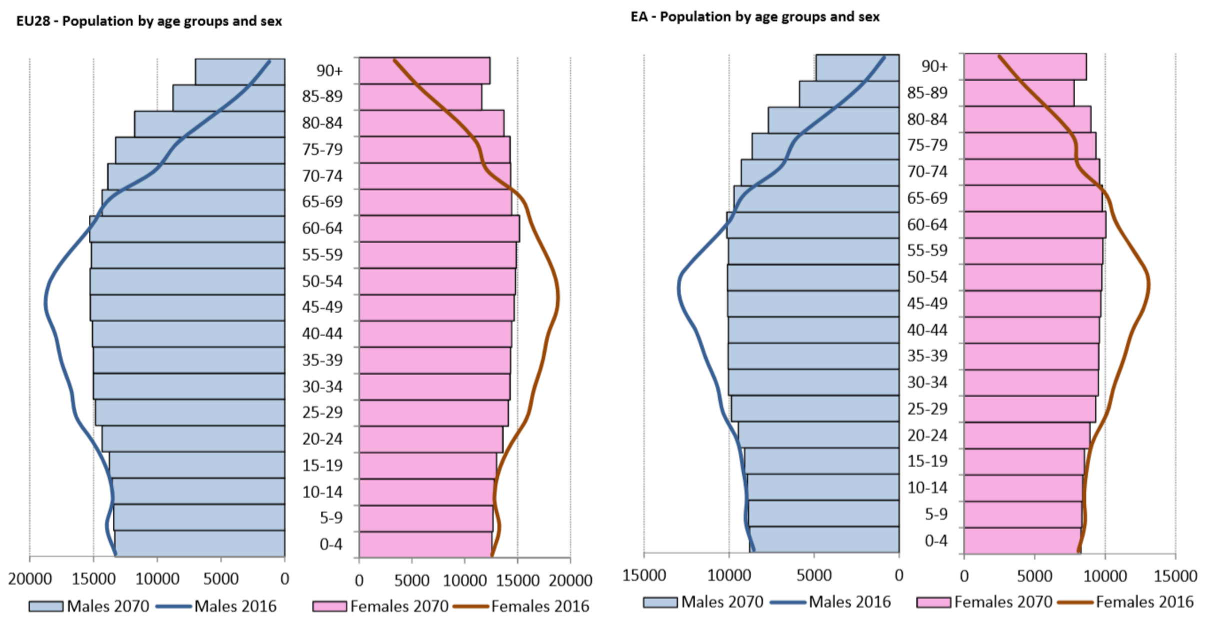
Governments and long-term care providers acknowledge the increasing role of the informal caregiver in the care for community-dwelling frail elderly and are aware of the need to support them in their role to ensure the sustainability of the long-term care system [8]. A variety of support measures and services for informal caregivers that aim at decreasing the negative consequences of providing informal care are made available [8, 9]. Yet underuse of available support measures and services is a problem among informal caregivers of community-dwelling frail elderly [9, 10]. To be able to understand how informal caregivers experience their caregiving role and how they experience support, research is needed that explores the concept of support for informal caregivers from the point of view of the informal caregiver.

Background

An ageing population

The world's population is ageing rapidly. It is expected that by 2050 up to 20% of the total population will be aged 60 years or more [11]. As for the very old, people aged 85 years and over, expectations are that the numbers are going to double over the next 20 years [12], with 50% of them having at least two chronic conditions (multi-morbidity) [13, 14]. The ageing of the population and the increase in people with multi-morbidity will have a major impact on the demand for long-term care services [3]. In the coming decades the demographic old-age dependency ratio in the European Union (EU) is expected to double between 2010 and 2070 (figure 1). In the EU the total population is estimated to increase from 511 million in 2016 to 520 million in 2070 but the working-age population (15-64) will decrease significantly from 333 million in 2016 to 292 million in 2070 due to fertility, life expectancy and migration flow dynamics [15]. Where in 2016 there were 3,3 people aged 15-64 for every person aged over 65 (29,6%), in 2070 it is expected to be a 2 for 1 ratio (51,2%). This will have an impact on available workforce for the growing group of older people [15].

Figure 1: European population by age group and gender, 2016-70 (thousands)



EU28 = all 28 member states of the European Union (including the UK); EA = Euro-Area, 19 member states which have adopted the euro (€)

Source: Commission services, Eurostat. European Commission, *The 2018 ageing report: Economic and budgetary projections for the EU member states (2016–2070).* Institutional Paper No. 79. Luxembourg: Publications Office of the European Union, 2018.

Frail elderly

Frailty is a dynamic and complex aging process in which a frail older person experiences losses in one or more domains of physical, psychological, cognitive and social functioning. When frail elderly people are exposed to certain stressors, such as the loss of a partner, a fall or a disease, they have an increased risk of a greatly deteriorated health condition and loss of self-reliance [16, 17]. More than a quarter of people older than 85 years are estimated to be frail with an increased risk of adverse outcomes [18]. This puts a burden on existing health care systems [19].

Governments are acknowledging this and are promoting initiatives that aim at maintaining the frail elderly at home longer and delaying nursing home admission. Innovative and integrated services to maintain the frail elderly at home for as long as possible are therefore being implemented in several countries. In 2009, the Belgian Federal Government has launched a financing program through the National Institute for Health and Disability Insurance (NIHDI) for innovative bottom-up projects for the care and support of frail older people who prefer to maintain living at home. These health care innovation projects, spread across Belgium, aimed at reducing the institutionalization risk for the frail elderly [20]. Because of the heterogeneity of the projects and their target populations, the manifestation of frailty in their clients could be very diverse. Therefore the projects were allowed to choose between two different scales to measure frailty in order to include frail older people in the projects. One scale was the Edmonton Frail Scale [21] with a cutoff point of 6. The other scale was an adapted version of the Katz scale for Belgian home care and residential care. Older people having a dependence status of A, B or C (home scale) or B, C or Cd (residential scale) could be included [20]. Besides these two scales, older people who had been diagnosed with dementia by a geriatrician, neurologist or psychiatrist were also considered to be frail and could be included in the projects [20].

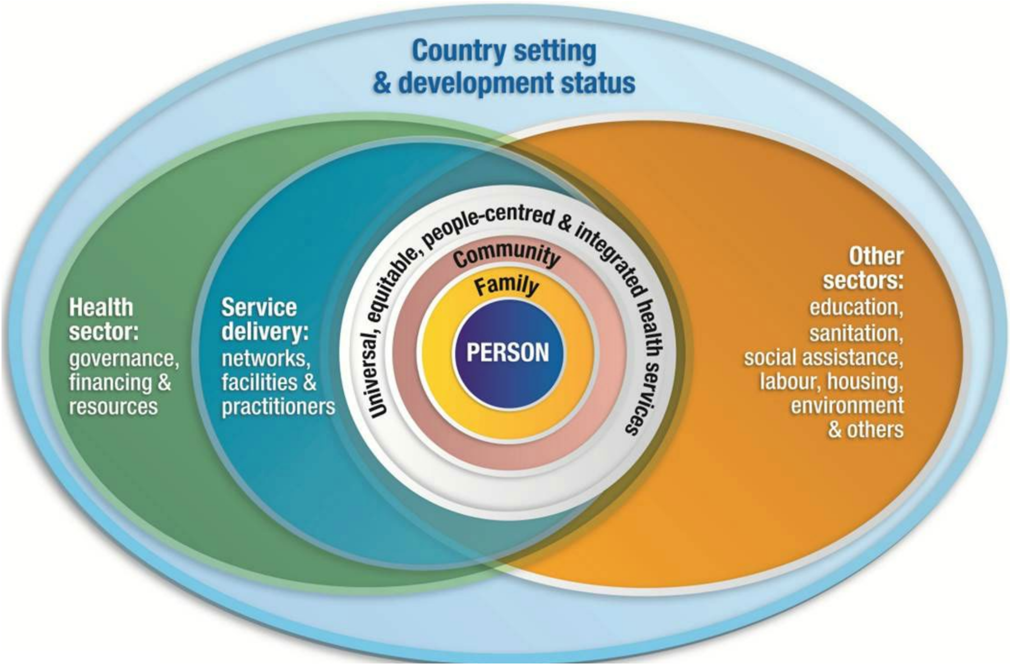
A large part of existing literature in the field of frailty consists of epidemiological studies, studies on the association between frailty and adverse outcomes or the development and implementation of tools for detection and measurement of frailty [19]. In other words, the focus in frailty studies is mainly on the frail older person and his health status. Seen the frail older person’s increasing dependency on others as their health status declines, this increased need for care also puts pressure on their caregivers [22].

Informal caregivers

When getting older, a large majority of people prefer to be cared for at home by informal caregivers instead of moving into a nursing home [5, 23].

The WHO framework on integrated people-centred health services positions the family as the first protective and supportive layer around the person with a care need (figure 2). Informal caregivers, usually family members, play a central and bridging role in the care between the frail older person and other informal and formal care providers and services [24].

Figure 2: WHO framework on integrated people-centred health services



Various definitions of an 'informal caregiver' can be found in literature. When reviewing these definitions some essential elements can be identified [25]. Informal care is generally described as extra care provided to a care-demanding person in the own social network. In this thesis, in the context of caring for frail older persons, an informal caregiver is defined as "a person who provides unpaid extra care to a frail older person living inside or outside his own household with whom he has a socio-emotional relationship like a relative, friend or neighbor. The extra care is provided on a regular basis but not through a professional or volunteer organization."

The proportion of non-institutionalised people over the age of 65 receiving informal care in Europe is on average 29% and increases with age; the average for people aged 80 years and older is 47.5% [5]. Informal care for community-dwelling frail older people is mainly provided by relatives, especially spouses and adult children [26]. The majority of these informal caregivers are female, mostly daughters, daughters-in-law and wives of the frail older person [5].

In the care for the older people, female adult-child caregivers may experience additional stressors, as compared with spouse caregivers [27]. Because of their age, usually between 30 and 65, female adult-child caregivers (daughters) often experience significant life events like getting married, having children and grandchildren, being professionally active while simultaneously caring for an ageing parent. As daughters are an important corner stone in delivering care, it is important that their unique experiences and needs are addressed.

While many informal caregivers report positive attitudes towards caring, it can also be challenging and may cause the informal caregiver to experience physical and mental health problems, financial problems and social isolation. A negative appraisal of the caregiving situation by the informal caregiver can lead to a state of subjective burden characterized by among others fatigue and stress.

Many studies in the field of informal care focused on measuring the burden caused by providing care [22]. However, quantitative burden measures do not always provide enough detail about the source of the burden [28]. Few studies paid attention to the real experiences of people caring for a loved one. To be able to describe the real caring experience of informal caregivers - and hence to improve support measures - more research is needed that can reveal their underlying thoughts and feelings, even inner feelings such as guilt.

Support for informal caregivers

Governments and long-term care providers acknowledge the increasing role of the informal caregiver in the care for community-dwelling frail elderly and are aware of the need to support them in their role to ensure the sustainability of the long-term care system [8]. A variety of support measures and services for informal caregivers that aim at decreasing the negative consequences of providing informal care are made available [8, 9]. Anthierens et al (2014) studied support measures for informal caregivers of dependent older people in the macro-institutional context in Belgium and in four other European countries (i.e. France, Germany, The Netherlands and Luxembourg) [9]. Depending on the context in the various countries, support measures included financial support as a compensation for the care work, access to social security benefits, working time reduction policies and respite and psychosocial support. The different support measures could be classified into 2 main groups based on the aim of the support measure. Either support measures that aim to avoid loss of income of the informal caregiver (cash-for-care allowances, flexible work hour schedules,…) or support measures that aim to improve the (mental) health of the informal caregiver (psychosocial support, respite,…).

In 2016 the Flemish minister for Welfare, Public Health and Family introduced a multi-year plan (2016-2020) that set the outlines for further expansion of the formal support offer for informal caregivers and strengthening cooperation between informal and professional care [8]. This informal care plan and the large-scale investigation among informal caregivers that preceded it were important milestones in the recognizing and supporting of caregivers [29].

Support for informal caregivers is getting more attention thanks to such initiatives as the Flemish informal care plan and largescale research studies, some of which funded by governments, that include interventions to support for informal caregivers [9, 29-31]. However, underuse of available support measures and services is still a notable problem among informal caregivers of community-dwelling frail elderly [9, 10]. The underuse can be partly explained by sociodemographic and cultural barriers but a better understanding of the reasons for not using support services is needed [9, 10]. Not in the least for non-cohabiting daughters who report the lowest frequency of support service usage, compared to cohabiting daughters, wives and other supporting relatives [32].

To be able to understand how informal caregivers experience their caregiving role and how they experience support from others, research is needed that explores the concept of social support for informal caregivers from their own point of view. In this thesis, social support for informal caregivers is studied from the point of view of the primary informal caregiver caring for frail older persons. It can be support from family and friends as well as from professional caregivers. Not only the social support they receive, but certainly also how they perceive social support will be studied. Support measures that aim to avoid loss of income of the informal caregiver (cash-for-care allowances, flexible work hour schedules,…) will therefore not be studied in this thesis.

Social support

Social support can be defined as *"The perceived or actual instrumental and/or expressive provisions supplied by the community, social networks and confiding partners"* [33].

Perceived support is the individual's subjective evaluation of the quality, adequacy and availability of support when needed [33-35]. The actual (or received) support refers to objectively observable acts of support [33-35]. A common classification of the concept social support is the classification into structural and functional social support. The structural dimension of social support refers to the nature of and ties between the individual's social support systems, from close family relationships over individual social networks of family and friends to the community the person lives in. The functional dimension of social support refers to the types of support that can be provided. Functional support can be classified into instrumental and expressive social support, as also in the above definition of Lin et al (1986). Instrumental support is the provision of practical help with daily household activities or care activities normally provided by the informal caregiver to the frail older parent. This can be a sibling that takes over tasks like grocery shopping or cleaning on a regular basis or during absence of the primary informal caregiver. Or it can be for example help from a nurse to assist the parent in personal hygiene. Expressive support involves psychosocial and emotional support provided by family, friends or professional caregivers in an attempt to make the informal caregiver feel better, encourage and give strength.

Studies on social support in the context of informal caregiving show positive effects on psychological outcomes like subjective burden [35, 36]. In a recent comprehensive meta-analysis, del Pino Casado et al (2018) studied the association between social support and burden in caregivers of adults and older adults [35]. They highlight that especially 'perceived' social support (the individual's subjective evaluation of the quality, adequacy and availability of support when needed) is more related to subjective burden than the actual 'received' social support. Satisfaction with support is a key factor in the effectiveness of social support for managing stress [37].

From idea to PhD

The idea for this doctoral thesis arose when I was interviewing healthcare professionals in the Protocol 3 projects [20]. Many healthcare professionals in the projects emphasised the important role of informal caregivers in being able to maintain homebased care for community-dwelling frail older persons. Although the main focus of the projects was on the frail older persons, some projects also included interventions aimed at supporting the informal caregiver directly like respite care or psychological support.

My interest in the informal caregivers caring for frail older persons and their need for support in order to maintain their important role led me to explore that area more in the form of a doctoral thesis.

Although the central focus throughout the entire trajectory was always on the importance to support informal caregivers of community-dwelling frail older persons, we decided not to fix the entire research process already from the start. We allowed the results of our studies to influence the choice of focus and methodology for next studies. This led us to make the choice at a certain point to focus more on social support as it appeared to have an important impact on how the informal caregivers in the interview study experienced providing care.

Aim and research questions

Aim

The overall aim of this doctoral thesis is to explore the concept of (social) support for informal caregivers caring for frail older persons from the point of view of the primary informal caregiver. The different studies bundled in this thesis will add to a better understanding of how informal caregivers of community-dwelling frail older people experience providing informal care and how they experience social support in this role.

Research questions

- ✓ What are the known effects of different types of support services targeting informal caregivers of community-dwelling frail elderly?
- ✓ How do non-cohabiting adult daughters experience caring for their community-dwelling frail elderly parents?
- ✓ What elements are central in the process of accepting social support when caring for a community-dwelling frail older parent?
- ✓ What is the relationship between perceived social support and subjective burden in providing informal care to community-dwelling frail elderly?

Social support for informal caregivers of community-dwelling frail elderly		
Systematic review	What are the known **effects of different types of support services** targeting informal caregivers of community-dwelling frail elderly? *Chapter 2*	
Qualitative longitudinal research design	How do non-cohabiting adult daughters **experience caring** for their community-dwelling frail elderly parents? *Chapter 3*	What elements are central in **the process of accepting social support** when caring for a community-dwelling frail older parent? *Chapter 4*
Quantitative cross-sectional research design	What is the **relationship between perceived social support and subjective burden** in providing informal care to community-dwelling frail elderly? *Chapter 5*	

Outline of the thesis

Chapter 1 contains an **introduction** and provides **background** information on the research topic which is social support for informal caregivers of community-dwelling frail older people.

The body of the thesis consists of 4 substantive chapters (chapter 2-5). In each chapter one of the research questions of this work is dealt with. The chapters have been drawn up in the form of scientific publications and can also be read separately.

Chapter 2 reports the **systematic literature review** performed at the start of the study. The aim of this systematic review was to broadly review the best evidence on different types of support services targeting informal caregivers of community-dwelling frail elderly. The research question answered in this chapter is: ***What are the known effects of different types of support services targeting informal caregivers of community-dwelling frail elderly?***.

Chapter 3 reports the results of a **descriptive qualitative study** to better understand the experiences of adult daughters caring for an ageing parent. To be able to provide the most appropriate social support it is important to understand the experience of caring for a frail older person from the point of view of the informal caregiver. The research question in this chapter is: ***How do non-cohabiting adult daughters experience caring for their frail ageing parents who live in their own homes?***

Chapter 4 reports the results from a **longitudinal qualitative study** with the same participants as in the descriptive qualitative study reported in chapter 3. The advantage of conducting a longitudinal qualitative study was that it allowed to get insight in the process of accepting social support when caring for a frail older parent. The research question in this chapter is: ***What elements are central in the process of accepting social support when caring for a frail older parent?***

Chapter 5 reports the results from a **largescale descriptive cross-sectional study** analysing the association between informal caregiver's subjective burden and perceived social support in providing informal care to frail older people. The idea for this quantitative study is based on a hypothesis that emerged from the descriptive qualitative study in chapter 3 that informal caregivers who experienced more social support tended to report less indicators for caregiver burden. The research question in this chapter is: ***What is the relationship between perceived social support and subjective burden in providing informal care to community-dwelling frail older people?***

Chapter 6 provides a **general discussion** of the findings from the different studies bundled in this thesis. The research questions are answered and put into context of current literature, policy and practice. Strengths and limitations of the studies are discussed and recommendations for future research and practice are presented.

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Chapter 2

The effect of caregiver support interventions for informal caregivers of community-dwelling frail elderly: a systematic review

Published as

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Abstract

Introduction

Informal caregivers are important resources for community-dwelling frail elderly. But caring can be challenging. To be able to provide long-term care to the elderly, informal caregivers need to be supported as well. The aim of this study is to review the current best evidence on the effectiveness of different types of support services targeting informal caregivers of community-dwelling frail elderly.

Methods

A systematic literature search was performed in Medline, PsychINFO, Ovid Nursing Database, Cinahl, Embase, Cochrane Central Register of Controlled Trials and British Nursing Index in September 2010.

Results

Overall, the effect of caregiver support interventions is small and also inconsistent between studies. Respite care can be helpful in reducing depression, burden and anger. Interventions at the individual caregivers' level can be beneficial in reducing or stabilizing depression, burden, stress and role strain. Group support has a positive effect on caregivers' coping ability, knowledge, social support and reducing depression. Technology-based interventions can reduce caregiver burden, depression, anxiety and stress and improve the caregiver's coping ability.

Discussion

Integrated support packages where the content of the package is tailored to the individual caregivers' physical, psychological and social needs should be preferred when supporting informal caregivers of frail elderly. It requires an intense collaboration and coordination between all parties involved.

Key words

frail elderly, caregivers, health services - needs & demands

Introduction

The main challenge in primary health care is the ageing population and the accompanying multimorbidity, long-term care demands and costs. In the industrialized world, 25% of 65–69 year olds and 50% of 80–84 year olds are affected simultaneously by two or more chronic health conditions and need long-term care [1, 2]. It is estimated that the share of people over 80 years old will rise from 4% in 2010 to nearly 10% in 2050 [2]. Long-term care spending will rise accordingly. Across all OECD countries, long-term care costs now account for 1.5% of the gross domestic product (GDP) on average [2].

The frail elderly are either being cared for at home by formal and informal caregivers, or in nursing homes [3]. In order to be able to stay at home, elderly in need of long-term care require a range of services, health care as well as social services. Despite the fact that around 70% of long-term care users receive services at home, institutional care costs account for 62% of total spending in long-term care [2]. Governments are acknowledging this and are promoting initiatives that aim at maintaining the frail elderly at home longer and delaying nursing home admission. Innovative and integrated services to maintain the frail elderly at home for as long as possible need to be implemented.

The effectiveness of interventions to maintain independent living in elderly people has been profoundly studied in a systematic review and meta-analysis by Beswick et al. (2008). They showed that complex interventions can help elderly people to continue living at home [4]. Hallberg and Kristensson (2004) performed a review on case management interventions for community- dwelling frail older people [5]. Strikingly they identified only a few studies focusing on a family-oriented approach, including support for informal caregivers.

Informal caregivers are important resources for community-dwelling frail elderly. However, caring can be challenging, causing physical and mental health problems[6], financial problems and social isolation [7]. Caregiver depression, stress or burnout, among others, increase the risk of institutionalization of the person being cared for [8]. In order to provide long-term care to the frail elderly, their informal caregivers need to be supported as well. Cost-effective caregiver support policies can reduce the demand for expensive institutional care [2].

Systematic reviews on support for informal caregivers already exist, but they are targeted at specific groups of caregivers according to the patient’s chronic condition, for example, dementia, cancer, palliative care [9] or one specific type of support like group support or respite care [10, 11].

We do not want to limit our review to a single type of support service and its effects, a specific subgroup of caregivers or a single type of study design. Clinicians, in particular general practitioners in primary care tend to work with a broad range of caregivers and patients irrespective of their diagnosis. Every care giving situation is different and most caregiver's needs cannot be answered by providing a single service. Therefore the aim of this study is to broadly review the current best evidence on different types of support services targeting informal caregivers of community-dwelling frail elderly.

Our research question is formulated using the PICO method [12]. ***What are the known effects of different types of support services targeting informal caregivers of community-dwelling frail elderly?***

The population (P) studied is the informal caregivers of community-dwelling frail elderly. For this study we define an informal caregiver as a person who provides care to a relative, friend or neighbour in need of long-term care on a regular basis, not through a professional or volunteer organization. There has to be a personal relationship between the caregiver and the care recipient. The community-dwelling frail elder in this study is a vulnerable older person still living at home but dependent on others for one or more Activities of Daily Life (ADL) on a long-term basis. The frail older person's impairment is not linked to specific conditions.

As intervention (I) to be studied we are interested in a broad range of possible support services targeting informal caregivers. Studies comparing (C) different forms of support as well as studies comparing a form of support to usual care are eligible for inclusion.

We do not focus on a single caregiver-related outcome (O). We want to give an overview of the different outcome measures used in the included studies.

Methods

Search strategy and eligibility criteria

The methodology outlined in the Prisma Statement [13] was used as a guide for this systematic review. A literature search in Medline, PsychINFO, Ovid Nursing Database, Cinahl, Embase, Cochrane Central Register of Controlled Trials and British Nursing Index was carried out in September 2010. The search was limited to reviews and additional original effectiveness studies published in English, French, German or Dutch. A combination of indexing (Mesh) terms and free-text keywords concerning informal caregivers, frail elderly, caregiver needs and support interventions was used to find relevant articles. A detailed overview of the electronic search strategies used in the different databases is presented in table 1. The multiple database search provided a total of 912 titles. After removing duplicates, 696 unique titles were stored in an EndNote X3 database.

Table 1: Search strategy

Database	Search strategy		Hits
Medline	#1	Caregivers OR Home Nursing	20985
	#2	Frail Elderly	4914
	#3	Health Services Needs and Demand OR Health Services	1290975
	#4	need or needs or demand or demands or wish or wishes or requirement or requirements or service or services or support or help	6525249
	#5	#3 OR #4	7171775
	#6	#1 AND #2 AND #5	452
	#7	**Limit #6 to (Dutch OR English OR French OR German)**	**427**
PsychINFO	#1	Caregivers or Home Care or Elder Care	17175
	#2	frail elderly	656
	#3	Needs or Health Service Needs or Psychological Needs or Needs Assessment	11799
	#4	need or needs or demand or demands or wish or wishes or requirement or requirements or service or services or support or help	653011
	#5	#3 OR #4	653011
	#6	#1 AND #2 AND #5	176
	#7	**Limit #6 to (Dutch OR English OR French OR German)**	**176**
British Nursing Index	#1	Carers	2542
	#2	frail elderly	66
	#3	need or needs or demand or demands or wish or wishes or requirement or requirements or service or services or support or help	42171
	#4	**#1 AND #2 AND #3**	**6**
Ovid Nursing Database	#1	Home Nursing OR Caregivers	7817
	#2	Frail Elderly	1025
	#3	Health Services Needs and Demand OR Health Services	242104
	#4	need or needs or demand or demands or wish or wishes or requirement or requirements or service or services or support or help	195058
	#5	#3 OR #4	324111
	#6	#1 AND #2 AND #5	134
	#7	**Limit #6 to (Dutch OR English OR French OR German)**	**130**
CINAHL	#1	Caregivers	11251
	#2	Frail Elderly	2122
	#3	Health Services Needs and Demand or Information Needs or Needs Assessment	20779
	#4	need or needs or demand or demands or wish or wishes or requirement or requirements or service or services or support or help	447445
	#5	#3 OR #4	447610
	#6	#1 AND #2 AND #5	108
	#7	**Limit #6 to (Dutch OR English OR French OR German)**	**103**
Cochrane Central Register of Controlled Trials	#1	Caregivers	941
	#2	Frail Elderly	416
	#3	Health Services Needs and Demand	500
	#4	Health Services	55598
	#5	#3 OR #4	55763
	#6	need or needs or demand or demands or wish or wishes or requirement or requirements or service or services or support or help	239268
	#7	#5 OR #6	258091
	#8	**#1 AND #2 AND #7**	**31**
Embase	#1	Caregiver Limit to (Dutch OR English OR French OR German)	16045
	#2	carer OR (family AND caregiver) OR (spouse AND caregiver) OR (informal AND caregiver) Limit to (Dutch OR English OR French OR German)	13603
	#3	#1 OR #2	21368
	#4	Frail Elderly Limit to (Dutch OR English OR French OR German)	998
	#5	Health service Limit to (Dutch OR English OR French OR German)	1485357
	#6	Human needs Limit to (Dutch OR English OR French OR German)	923
	#7	need or needs or demand or demands or wish or wishes or requirement or requirements or service or services or support or help	4459671
	#8	#5 OR #6 OR #7	4459671
	#9	**#3 AND #4 AND #8**	**39**

Mesh terms are underlined

Study selection procedure

The selection procedure is presented in a flow diagram in figure 1.

Step 1: review of reviews

Initially we only focused on the reviews. From the 696 unique references in our Endnote X3 database, 226 references contained the word review in any field. These references were screened on title and abstract by two researchers (MLH and JW). Reviews were included if they described community-based support services. The primary subject of the review had to be the informal caregiver and the informal caregiver had to care for a community-dwelling frail elder. Reviews about studies conducted in developing countries were excluded because of the difference in availability of formal support services. Most of the articles did not have the caregiver as the primary subject of the study, therefore they were excluded. After selection, 17 review articles remained to be assessed for methodological quality.

Step 2: review of primary studies

In a second step we went back to the set of 696 references to find additional primary studies that were not yet included in the selected review articles. All 696 articles were screened on title and abstract by two researchers (MLH and VV). This resulted in 71 articles that were eligible for assessment of the full text. After verifying that the articles met our inclusion criteria, 24 articles remained to be assessed on methodological quality.

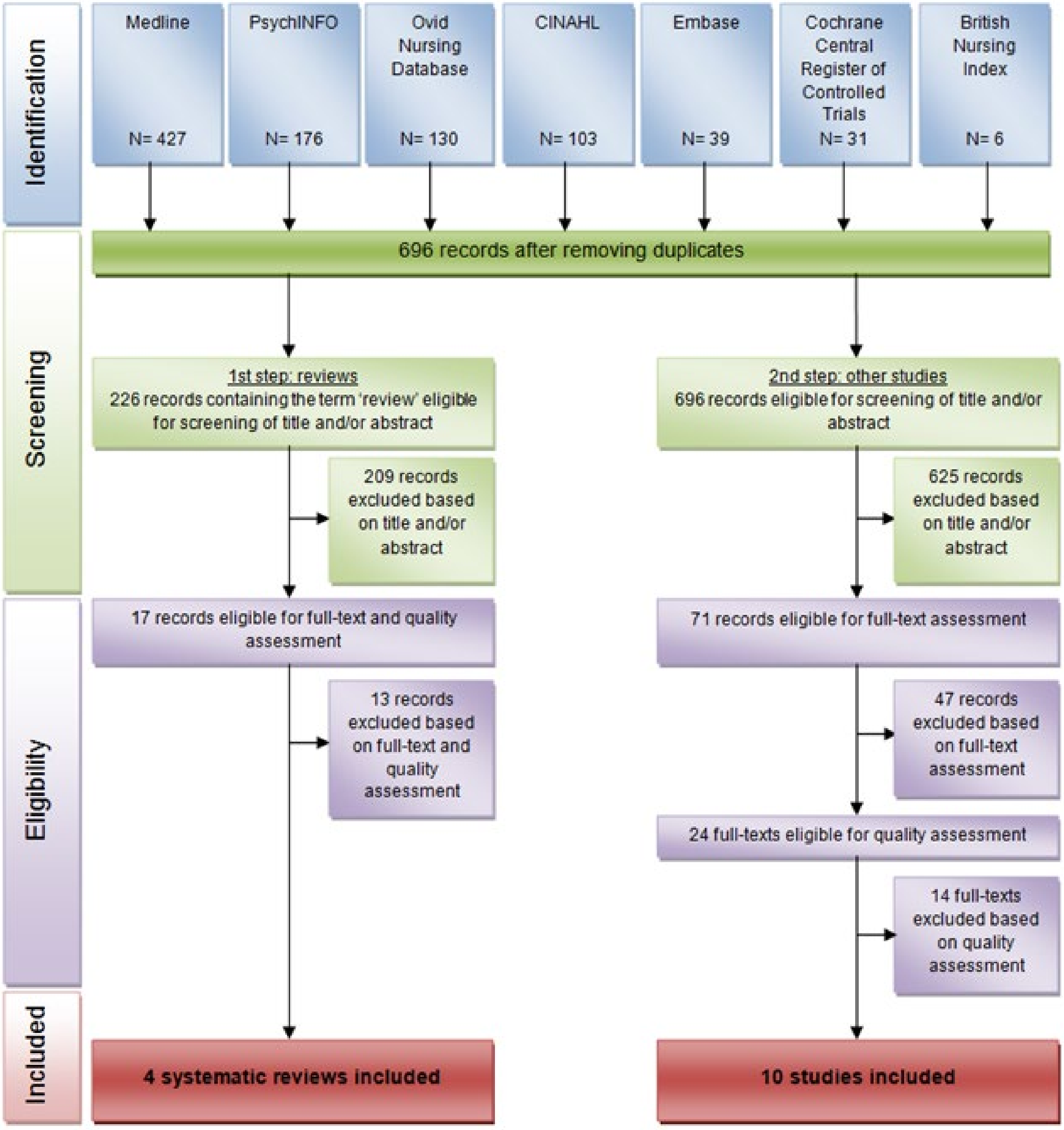
Quality assessment

The methodological quality of the studies was assessed using the Scottish Intercollegiate Guidelines Network's (SIGN) methodology checklists [14]. Each study was assessed independently by two researchers (MLH and JW or RR or VV). Assessments were compared and discussed until mutual agreement. Only the articles that scored 10 out of 15 or more on quality were included in our literature review.

After consensus, four review articles were included [10, 11, 15, 16] and 13 review articles were excluded. Five of the excluded articles were actually not reviews, one was a duplicate, one was out of scope and six reviews did not meet our baseline quality score of 10 out of 15.

After quality appraisal of the additional primary studies, 10 articles were included in this review [17-26]. Three of these included articles [24-26] report on the same study but describe different outcomes (short-term, long-term and costs). Fourteen additional articles were excluded because of low quality scores.

Figure 1: Study selection flow diagram (Prisma)



Results

This literature review will provide an overview of the relevant literature on the effects of different types of caregiver support. Results from four systematic reviews [10, 11, 15, 16] and 10 additional primary articles [17-26] will be discussed. Characteristics of the included studies are listed in tables 2 and 3.

Table 2: Characteristics of included reviews

Systematic review	Intervention type in included studies (N)	Caregiver-related outcome measures
Mason, 2007	Respite care (42) – reviews (20) – day-care (8) – in-home respite (5) – respite packages (4) – host family (2) – institutional respite (1) – multidimensional package (1) – video respite (1)	– carer burden – mental/psychological health – physical health – quality of life – satisfaction – time spent on caring tasks – utilization of any health and social services – utilization of informal or voluntary support services
Shaw, 2009	Respite care (104 quantitative; 70 qualitative) – day care – institutional – in-home – mixed	– anger and hostility – anxiety – burden – depression – morale – quality of life
Cassie, 2008	Psychosocial interventions (16) – meta-analyses (3) – individual (4) – group (4) – multi-modal (3) – technology-based (2)	– anxiety – attitudes – bother – burden – depression – fatigue – knowledge – knowledge of community resources – management of behaviour problems – social support – stress – tension
Magnusson, 2004	Information and Communication Technology (139)	– stress – coping

Table 3: Characteristics of included primary studies

	Study design	Research question (hypothesis)	Population	Intervention	Caregiver-related outcome measures and instruments
Horton-Deutsch et al., 2002	Quasi-experimental	Hypothesis: After the intervention, caregiver participants will experience significantly lower levels of depression and global role strain and significantly higher levels of satisfaction and physical health than caregivers in the control group.	TG: 13 CG: 12	Individual support (in-home) - Period: 2 months - Intensity: average of 9 home visits, each averaging 1 hour and 15 minutes - Interventionist: Nurse	**Depression**: Center for Epidemiologic Studies – Depression Scale (CES-D) (Radloff, 1977) **Global Role Strain**: Role Strain Scale (Archbold et al., 1990) **Satisfaction**: Caregiver satisfaction (Lawton et al., 1982) **Physical health:** Caregiver physical health (Miller & Towers, 1991)
Melis et al., 2009	RCT	Hypothesis: The intervention will have a beneficial effect on caregiver burden.	TG: 61 CG: 49	Individual support (in-home) - Period: 3 months - Intensity: average of 3.8 visits (SD 1.3), each averaging 1.3 hours - Interventionist: Nurse	**Burden**: Zarit Burden Interview (ZBI) (Zarit)
Toseland et al., 2006	RCT	Hypothesis: Compared to caregivers receiving usual care, caregivers in HEP will experience significant reductions in outpatient costs. Spouses of caregivers participating in the intervention will experience significant reductions in outpatient, inpatient and total costs.	TG: 58 CG: 47	Group support - Groups of 5 to 8 participants - Period: 12 moths - Intensity: 8 weekly, 2-hour sessions and 10 monthly 2-hour follow-up group sessions. - Group leader: Master in Social Work	**Costs**: • outpatient costs • inpatient costs • emergency room costs • drug costs • total costs
Toseland et al., 2004	RCT	Hypothesis: Compared to caregivers receiving usual care, caregivers in the intervention will experience **long-term** improvements in: • Perceived health status • Emotional well-being • Social support • Subjective caregiving burden • Knowledge of caregiving resources • Pressing problems • Self-appraisal of change.	TG: 58 CG: 47	Group support - Groups of 5 to 8 participants - Period: 12 moths - Intensity: 8 weekly, 2-hour sessions and 10 monthly 2-hour follow-up group sessions. - Group leader: Master in Social Work	**Psychosocial well-being** General Health Questionnaire (GHQ) (Goldberg and Hillier, 1979) **Perceived social support** Social Provision Scale (SPS) (Cutrona, Russell & Rose, 1986) **Perceived health status** The Medical Outcome Study Short-Form Health Survey (MOS SF-36) (Ware et al, 1994) **Subjective and objective burden** Montgomery-Borgatta Burden Scale (MBBS) (Montgomery & Borgatta, 1986) **Pressing problems** Pressing Problems Index (PPI) (Developed for this study, previous versions used by Toseland and colleagues, 1995, 1992, 1989) **Knowledge of caregiving resources** Knowledge and use of community services scale (CSS) (Developed for a previous study (Toseland et al, 1989) and modified and used in several studies by Toseland and colleagues, 1995, 1992) **Self-appraisal of change** Self-Appraisal of Change Scale (SAC) (Developed for this study (Toseland et al, 2001))

	Study design	Research question (hypothesis)	Population	Intervention	Caregiver-related outcome measures and instruments
Toseland et al., 2001	RCT	Hypothesis: Compared to caregivers receiving usual care, caregivers in the intervention will experience **short-term** improvements in: • Perceived health status • Emotional well-being • Social support • Subjective caregiving burden • Knowledge of caregiving resources • Pressing problems	TG: 58 CG: 47	Group support - Groups of 5 to 8 participants - Period: 12 months - Intensity: 8 weekly, 2-hour sessions and 10 monthly 2-hour follow-up group sessions. - Group leader: Master in Social Work	**Psychosocial well-being** General Health Questionnaire (GHQ) (Goldberg and Hillier, 1979) **Perceived social support** Social Provision Scale (SPS) (Cutrona, Russell & Rose, 1986) **Perceived health status** The Medical Outcome Study Short-Form Health Survey (MOS SF-36) (Ware et al, 1994) **Subjective and objective burden** Montgomery-Borgatta Burden Scale (MBBS) (Montgomery & Borgatta, 1986) **Pressing problems** Pressing Problems Index (PPI) (Developed for this study, previous versions used by Toseland and colleagues, 1995, 1992, 1989) **Knowledge of caregiving resources** Knowledge and use of community services scale (CSS) (Developed for a previous study (Toseland et al, 1989) and modified and used in several studies by Toseland and colleagues, 1995, 1992) **Self-appraisal of change** Self-Appraisal of Change Scale (SAC) (Developed for this study (Toseland et al, 2001))
Toseland et al., 1992	RCT	Hypothesis: Significant positive changes in measures of pressing problems, perceived self- efficacy, knowledge and use of community resources, informal social support and self-ratings of personal change are expected. Less change is expected in the measures of burden, coping, depression, stress, anxiety and Satisfaction and change in spousal independence.	TG: 42 CG: 47	Group support - Groups of 5 to 9 participants - Period: 2 months - Intensity: 8 weekly 2-hour sessions. - Group leader: Master in Social Work with 8 years of experience	**Caregivers physical health status** Physical Symptoms Index of the Adult Health and Daily Living Form (HDL) (Moos et al, 1987) + 5 point scale (from very poor to excellent) **Burden** Montgomery-Borgatta Burden Scale (MBBS) (Montgomery & Borgatta, 1986) **Depression** Beck Depression Inventory (BDI) (Beck, 1967) + Geriatric Depression Scale (GDS) (Yesavage et al, 1983) **Anxiety** Spielberger State-Trait Anxiety Inventory (STAI) (Spielberger et al, 1970) **Perceived self-efficacy** 3-item index (Duncan & Liker, 1981) **Help seeking and coping** Help Seeking Coping Index and Index of Coping Responses (ICR) from the Health and Daily Living Form (HDL) (Moos et al, 1987) **knowledge and use of community Services** 1 question **Caregiver informal support network** Series of questions **Satisfaction and change in spousal independence** 5 point scale **Pressing problems** Identification and rating of problems **Personal change** Personal Change Scale (PCS) (Developed for this study) + Self-appraisal of change scale (Developed for this study) **Satisfaction** 5-point scale

	Study design	Research question (hypothesis)	Population	Intervention	Caregiver-related outcome measures and instruments
Smith et al., 2006	RCT	Hypothesis: Compared to caregivers receiving usual services, both types of caregivers in the intervention would experience short-term improvements in burden, depression, anxiety, social support, pressing problems and knowledge and use of community services.	Adult children: TG: 31 CG: 30 Spouses: TG: 22 CG: 14	Group support - Groups of 5 to 8 participants - Period: 3 moths - Intensity: 12 weekly, 90 minute sessions. - Group leader: Master in Social Work	**Burden** Zarit Burden Interview (ZBI) (Zarit) **Depression** Center for Epidemiologic Studies – Depression Scale (CES-D) (Radloff, 1977) **Anxiety** Stait-Trait Anxiety Inventory (STAI) (Spielberger, 1983) **Social support** Medical Outcome Study (MOS) Social Support Survey (SSS) (Sherbourne & Stewart 1991) **Pressing problems** Pressing Problems Index (PPI) (Toseland ea. used variations in previous research) **Knowledge and use of community services** Community Service Inventory (Developed for a previous study by Toseland ea.)
Demers et al., 1996	Quasi-experimental	Hypothesis: The intervention will have an impact on the caregivers' level of subjective burden.	TG: 73 CG: 80	Group support - Groups of on average 8 participants - Period: 2,5 months (10 weeks) - Intensity: 10 weekly meetings of 2,5 hours each on average - Group leader: unknown	**Subjective burden** Zarit Burden Interview (ZBI) (Zarit et al 1980) **Degree of depression** Generalized Contentment Scale (GCS) (Hudson 1982) **Help provided by informal network** 2 questions **Self-perceived physical, mental and social health** 4 questions **Satisfaction with general health** 1 question
Dellasega et al., 2002	RCT	Hypothesis: It is expected that the intervention benefits family caregivers.	TG: 16 CG: 16	- Individual support (in-hospital, in-home and telephone) - Period: 1 month - Intensity: 1 in-hospital visit + 2 home visits at 48 hours and 1 to 2 weeks post-discharge + a phone call during the week between 2 home visits - Interventionist: Advanced Practice Nurse (APN)	**Stress** 2 subscales of the Caregiver Burden Index **Health and Well-being, financial status** Health and Daily Living Form (HDL) + additional item to identify time missed from work was related to caregiving activities
Colling et al., 2003	Quasi-experimental	Hypothesis: It is expected that the intervention has an effect on reducing caregiver burden	TG: 34 CG: 25	Individual support (in-home + telephone) - Period: 6 months - Intensity: home visits to teach caregivers and care recipients how to implement the toileting regimen + weekly follow-up telephone calls. They were accessible by pager at any time to answer questions. - Interventionist: research staff	**Caregiver burden, preparedness, and role strain measures** developed and tested over several years by Archbold and Stewart (1989) **Economic burden** 4item scale **Global Role Strain** 4item scale **Preparedness for caregiving scale** 6 item scale

TG = test group; CG = control group

Outcomes

The number of different outcome variables used in each study varies from one [21] to twelve [23] (tables 2 and 3). Caregiver burden and depression were measured the most. Burden was assessed using three different instruments: the Zarit Burden Index (by Zarit ea., 1980)[19, 21, 22], the Montgomery-Borgatta Burden Scale (by Montgomery & Borgatta, 1986)[23-25] and the Preparedness for Caregiving Scale (by Archbold ea., 1990) [17, 20]. Depression was assessed with six different scales or subscales: The Center for Epidemiologic Studies—Depression Scale (by Radloff, 1977) [20, 22], The General Health Questionnaire (by Goldberg & Hillier, 1979) [24, 25], the Beck Depression Inventory (by Beck ea., 1967)[23], the Geriatric Depression Scale (by Yesavage ea., 1983) [23], the Generalized Contentment Scale (by Hudson, 1982) [19] and the Health and Daily Living Form (Billings ea., 1983) [18].

Only the outcome variables that were used in at least two different studies are being discussed, namely: depression, burden, stress, role strain, anger, anxiety, quality of life, coping ability, knowledge of resources, social support and economic burden.

Types of support

Three main types of support are mentioned in the included studies: respite, psychosocial support and information and communication technology (ICT) support. Psychosocial support is studied at the individual caregiver's level as well as at group level.

The four reviews cover separately: respite services [10, 11], psychosocial interventions (individual and group interventions) [15] and ICT support services [15, 16]. The 10 primary studies report on psychosocial support interventions providing education, information, coordination, counselling, psychological and emotional support, either in group [19, 22-26] or at the individual caregiver level [17, 18, 20, 21].

The findings on these three main types of support will be discussed in the following paragraphs and will be summarized in table 4.

Table 4: Results from systematic reviews and primary studies

		Respite		**Psychosocial support**												**ICT**	
				Individual					**Group**								
		Shaw et al., 2009	**Mason et al., 2007**	**Cassie et al., 2008 (individual)**	Melis et al., 2009	Horton-Deutsch et al., 2002	Dellasega et al., 2002	Colling et al., 2003	**Cassie et al., 2008 (group)**	Toseland et al., 1992	Toseland et al., 2001	Toseland et al., 2004	Toseland et al., 2006	Smith et al., 2006	Demers et al., 1996	**Cassie et al., 2008 (ICT)**	**Magnusson et al., 2004**
Outcomes	Depression	+	+**	+		0	+*		+	0	+*	+*		+*	+*	+	
	Burden	+**	+		0			+*		+*	0	0			-*	+	
	Stress						+*			+*				+*			+
	Role strain					0					0	0		+*			
	Anger	+**															
	Anxiety	-							+							+	
	Quality of life	-**	-														
	Coping ability			+						+*	+*	+*		+*			+
	Knowledge of resources								+	+*	+*	+*		+*			
	Social support								+		+*			+*			
	Economic burden		-				+						+				

The studies in bold are reviews.
0: no effect
+: positive effect of the intervention on the measured outcome
-: negative effect of the intervention on the measured outcome
*: statistically significant (p<.05)
**: pooled effect sizes statistically significant (p<.05) (meta-analyses)

Respite

Respite services provide the caregiver with a temporary break in his care giving activities to improve the well-being of the caregiver. Two included systematic reviews report the effect of respite care on different caregiver outcomes.

Shaw et al. (2009) studied the effect of respite care on depression, burden, anger, anxiety and quality of life (table 3) [10]. Pooled results show a positive effect of respite on caregiver burden after 2–3 month's follow-up (Effect size (ES) -0.46; 95% Confidence interval (CI) -0.82 to -0.10) and after six months' follow-up (ES -0.58; CI -1.06 to -0.11). Respite care had a positive impact on caregivers' anger towards the care recipient (ES -0.38; CI -0.60 to -0.17). However, quality of life was significantly worsened after 6 to 12 months in caregivers receiving respite care (ES -0.22; CI -0.27 to -0.17). Although not statistically significant after pooling results, respite services tended to have a positive effect on depression and a negative effect on anxiety.

A systematic review and meta-analysis performed by Mason et al. (2007) studied the effect of respite care on caregivers' depression, burden, quality of life and economic burden (table 3) [11]. Mason et al. found a statistically significant positive effect of respite care on reducing depression (ES -0.32; CI -0.62 to -0.02) (table 3). Respite care tended to have a positive effect on decreasing caregiver burden and a negative effect on improving quality of life although not significant. Economic evidence suggests that respite is at least as costly as usual care.

Psychosocial support

At the individual caregivers' level

Contrary to respite services, where caregivers are provided a temporary break from caring, psychosocial support interventions aim at improving the caregivers' ability to manage the caregiving situation. These services offer packages including education, skill-building, counselling, information and emotional support. The support is mostly given in the caregiver's home. Cassie et al. (2008) reviewed studies evaluating individual support for caregivers [15]. They found that interventions at the individual caregivers' level decrease caregiver depression (table 3). They also improve the care givers' coping ability.

A randomized controlled trial (RCT) performed in the Netherlands by Melis et al. (2009) tested the effect of a problem-based home visiting programme for frail elderly on caregiver burden (table 3) [21]. After 3 and 6 months, the treatment group did not show a significant decrease in burden compared to the control group. When analysing subgroups, caregivers sharing a household with the care recipient may have benefited, while the intervention might have had a negative effect on caregivers not living together with the frail older adult.

A quasi-experimental study by Horton-Deutsch et al. (2002) tested the effect of a multi component intervention for family caregivers [20]. No significant differences were found between treatment and control group for depression and global role strain (table 3). The study found an important difference between the 2 nurses who provided the intervention. After eight weeks, caregivers in the treatment group of nurse A spent less hours on care giving because their patients improved. The nurse was able to assist as well the caregiver as the patient. In the treatment group of nurse B, the patients deteriorated and the caregivers spent more hours on care giving.

Another RCT evaluating the effect of an advanced nursing practice intervention (Dellasega et al. 2002) found that the intervention had a positive impact on caregivers' outcomes (table 3) [18]. Caregivers in the treatment group had significantly fewer depressive symptoms after 2 weeks ($p \leq 0.05$) and still after 4 weeks ($p \leq 0.05$). Additionally, they had significantly lower stress scores after 48 hours ($p \leq 0.05$). Working caregivers also had fewer disability days and less financial loss.

While the content of the support intervention in the previous studies could vary according to the caregivers' needs, other individual interventions offer more defined educational and practical support like education about implementing a toilet regimen. Colling et al. (2003) performed a quasi-experimental study evaluating the effect of a continence program [17]. The study showed a significant decline in the caregivers' perceived burden (table 3).

Group interventions

In addition to the characteristics of interventions at the individual caregivers' level, group interventions also have a social dimension. The interaction between group members can have an effect on caregivers that is impossible to achieve with individual support.

According to the review performed by Cassie et al. (2008) group interventions decrease depression and anxiety, increase their knowledge of community resources and increase their social support (table 3) [15].

Toseland et al. (1992) performed an RCT to evaluate the effect of a group program for spouses of frail elderly veterans [23]. During 8 weeks spouses received weekly 2 hour group sessions. After the intervention no effect was found on depression. Significant decreases in subjective burden ($p=0.009$), and stress ($p=0.031$) were found (table 3). Also significant increases in the use of active behavioural coping strategies ($p=0.013$), personal changes in the ability to cope with the caregiving situation ($p<0.001$) and knowledge of community resources ($p=0.002$) were found.

Three articles (Toseland et al. 2001, 2004, 2006) report separately on the short-term effects (2001), long-term effects (2004) and cost evaluation (2006) of an RCT evaluating a Health Education Group Program (HEP) for caregivers [24-26]. The program is a multicomponent, psychoeducational intervention program delivered in a structured group format. Compared to the control group, short-term benefits for the caregivers in the experimental group were found in reducing depression ($p\leq0.05$). No effect was found on burden and role strain. The intervention increased coping ability ($p\leq0.01$), knowledge of community services ($p\leq0.01$) and social integration ($p\leq0.05$) (table 3). After one year the intervention was still effective in reducing depression ($p\leq0.05$), increasing coping ability and knowledge of community services ($p\leq0.01$) (table 3). Still no positive effects were found on burden and role strain. The results of the cost-effectiveness study indicate that total costs and outpatient costs were significantly lower in the intervention group compared to the control group (table 3).

Smith and Toseland (2006) adapted the design of the HEP to create a telephone support program for caregivers [22]. Results show that the intervention had a strong positive effect on the adult child caregivers, but no effect on the spouse caregivers. Adult child caregivers had a greater reduction in depressive symptoms ($p \leq 0.05$), stress of pressing problems ($p \leq 0.05$), role strain ($p \leq 0.05$) and personal strain ($p \leq 0.001$). They felt more effective in coping with pressing problems ($p \leq 0.05$). There was also a significant increase in knowledge of community services ($p \leq 0.001$) and in social support ($p \leq 0.01$) (table 3).

A quasi-experimental study by Demers and Lavoie (1996) showed contradictory results (table 3) [19]. The intervention had a stabilizing effect on the level of depressive symptoms in the treatment group ($p < 0.05$) but they experienced an unexpected increase of subjective burden ($p < 0.05$), while caregivers' burden in the control group decreased.

Information and communication technology

More recent literature focuses on the effect of information and communication technology to support caregivers. Cassie et al. (2008) reviewed the use of telephone and computer services to provide support and education to caregivers at home [15]. They found that technology-based interventions could reduce depression, burden and anxiety (table 3). Magnusson et al. (2004) conclude that information and communication technology interventions could reduce caregiver stress and promote optimal coping (table 3) [16].

Discussion

Evidence

This systematic overview identifies different types of interventions to support informal caregivers of community-dwelling frail elderly. The evidence is summarized in table 3. Some evidence exists for the effectiveness of respite care, interventions at individual caregiver level, group support and information and communication technology. Overall, the effect of caregiver support interventions is small and also inconsistent between studies.

Respite care can be helpful in reducing depression, burden and anger. Anxiety and quality of life do not seem to improve when offering respite services.

Interventions at the individual caregiver level can be beneficial in reducing or stabilizing depression, burden, stress and role strain. Surprisingly few studies evaluating individual interventions measure the caregivers' coping ability and knowledge.

Group support has proven to have a positive effect on caregivers' coping ability and knowledge as well as on social support. Studies evaluating group support find a positive effect of the intervention on caregivers' depression. The effect of group support on caregivers' burden is not consistent. Some studies find a positive effect, while others find no or negative effects. It is possible that participating in the group sessions causes burden instead of unburden the caregiver, while it may entail that the caregiver for example has to find sitting services for the elder during the group sessions.

Technology-based interventions can reduce caregiver burden, depression, anxiety and stress and improve the caregiver's coping ability.

No single intervention can answer all relevant physical, psychological and social needs of an informal caregiver caring for a frail elderly at home.

Integrated services

The term integration is often used differently in literature [27]. One can look at integration from a patients' as well as from a care provision perspective.

In a holistic patient-centred approach, support services should integrate all relevant physical, psychological and social needs of the patient. But needs from patients can differ from their informal caregivers' own needs. Support services targeting the needs of frail elderly are not necessarily concurrently beneficial for their informal caregivers. Therefore, integrated support services should pay special attention to supporting the caregivers' specific physical, psychological and social needs as well.

On the other hand, integration can also mean a collaboration between different professionals, within and between the cure and care sector, or within and between primary, secondary and tertiary care setting. Informal caregivers are important resources for frail elderly, but their contribution in the care as a care provider is often taken for granted [28]. Informal caregivers are often sandwiched between being a care provider and a person in need of care. It is important that this ambiguous position is acknowledged by professional care providers. Today, this is often not yet the case.

A well-supported informal caregiver is an essential partner in the long-term care for the frail elderly, since no professional care system will ever be able to cover all of the elder's needs [28]. Support for the informal caregiver should be integrated in all services aiming at delaying institutionalization of the frail elderly. In the future more research should be done on integrated services for the elderly that explicitly incorporate support for the informal caregiver.

Weaknesses

Using the search term Frail Elderly might not have captured all relevant articles concerning this population. Frail elderly as a concept is new in research literature. In Pubmed the Mesh-term Frail Elderly was introduced in 1991. Gobbens et al. (2010) reviewed the literature to identify the different definitions used to describe frail elderly and proposed a new conceptual definition of frailty [29].

In this study we reviewed the literature on the effectiveness of support services. The fact that we focused on quantitative data is a weakness. In addition to evidence of effectiveness, evidence of feasibility, appropriateness and meaningfulness found in qualitative studies could have told us a lot about how an intervention is related to the context in which it is given and how the intervention is experienced by the population.

The variety of outcome variables and measures used in the studies made it difficult to adequately compare results. When designing an evaluation study it is important to carefully select the most adequate outcome measures to assess interventions. Melis et al. (2009) only assessed the effect on caregiver burden and time spent on care [21]. No significant differences were found between study groups for these outcomes. However, concluding that the intervention did not benefit the caregivers is too premature. While the intervention mainly focused on advice and coordination of care, other outcome measures like coping ability or knowledge would also have been interesting to assess. Future research should pay special attention to matching the aim and content of the intervention to the most adequate outcome measures.

Strengths

We identified evidence for the effectiveness of caregiver support interventions irrespective of the elderly's disease entity. Caregiver needs are highly individual and can change over time. They are related to more aspects than only the elderly's health status. A profound assessment is essential to identify caregiver needs, priorities, cultural aspects and existing resources. Such an assessment will help clinicians to work out the most appropriate support strategy together with the caregiver. Often a combination of different types of services is necessary to answer the actual needs of the individual caregiver.

Recommendations for future research

More research is needed to explore the concept of optimal caregiver support. Who is best placed to perform a needs assessment and coordinate integrated caregiver support? Is it the role of the general practitioner or are in fact other professionals better placed? Caregivers exist all over the world, but their support needs can be different because of cultural habits and the healthcare system of the country they live in. In further research special attention should go to the influence of the caregivers' characteristics and context on the outcome.

Concerning the design of future studies, RCT's might not be the most adequate method to evaluate the effectiveness of caregiver support interventions. Other (mixed-) methods including economic evaluations and qualitative methods should be considered. At present, few studies did incorporate long-term effect evaluation. Future research should focus on the effect of integrated services over a longer period of time.

Conclusion

The heterogeneity in aim, content and intensity of the studied interventions demonstrates that defining 'best caregiver support' is not easy if not impossible.

While respite care is aimed at unburdening the caregiver by temporarily taking over the care for the elderly, psychosocial and educational support aims at strengthening the caregiver in his ability to better manage and cope with the care giving role.

Integrated support packages where the content of the package is tailored to the individual caregivers' physical, psychological and social needs should be preferred when supporting informal caregivers of frail elderly. It requires an intense collaboration and coordination between all parties involved.

Although this literature review does not have a direct link with integrated care, we are convinced that informal caregivers of community-dwelling frail elderly can benefit from integrated support services. Additionally, informal caregivers play an important role in the delivery of integrated care to the frail elderly. This paper may not add a lot of new insights to integrated care, however, the fact that this paper focuses on the informal caregiver in the first place instead of the patient is not common in existing research.

These findings are important for future programme development. In Belgium for instance, the central Government induced bottom up approach for new and innovative projects with a common purpose to keep frail elderly in their homes, including support for informal caregivers [30, 31]. To inform responsible stakeholders, evidence should be compiled and readily available. We hope that our contribution will support stakeholders when designing new avenues for the support of informal caregivers of community-dwelling frail elderly.

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Chapter 3

Understanding the experience of adult daughters caring for an ageing parent: a qualitative study

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Abstract

Introduction

The objective of this study is to describe how adult daughters experience caring for a frail older parent at home. In the near future the ageing of the population will have a major impact on the demand for formal and informal long-term care. Relatives, especially spouses and adult children are the main providers of informal care.

Methods

Qualitative research methodology was used to study the experience of adult daughters caring for their frail older parents. A phenomenological research perspective was used to better understand the daily experiences of caring for an ageing parent.

Data were collected using open-ended interviews. Interviews were audio recorded and transcribed verbatim. Data were subject to thematic analysis.

Results

Eleven women between 40–70 years of age participated in this study. Inductive coding of the interview data led to four main themes: being a caregiver as a natural process in life, the perception and consequences of caregiving activities, sharing care and finding a good balance between caring for an ageing parent and other responsibilities. Caregiving activities could be divided into visible and invisible activities and generated different feelings. The visible activities were more easily shared with other family members and professionals than the invisible ones. The women who struggled the most and tended to have a higher level of burden were those who experienced less support from their family.

Discussion

This study provided more insight into the experiences women have when caring for a parent. Supporting family networks that help in both visible and invisible activities may prevent overburden. Consumer-led care and the active participation of the informal caregiver in the decision-making process for building the care plan need to become more prominent.

Key words

chronic care, frail older persons, home care, informal caregiving, qualitative research

Introduction

In a recent study that evaluated projects providing alternative and supportive care to frail older persons living at home in Belgium [1], healthcare professionals emphasised the important role of informal caregivers in maintaining the frail older persons at home. Yet caring for a frail older person can be challenging, causing physical and mental health problems [2], financial burden and social isolation for the caregivers [3]. Further, caregiver depression, stress and burnout increase the risk of institutionalisation of the person being cared for [4]. Many studies in the field of informal care focused on measuring the burden caused by providing care [5]. However, quantitative burden measures do not always provide enough detail about the source of the burden [6]. Few studies paid attention to the real experiences of people caring for a loved one. More in-depth, usually emotionally charged information is needed from the informal caregivers to be able to describe the caring experience and improve support measures for informal caregivers.

The ageing of the population and the increase in people with one or more chronic diseases will have a major impact on the demand for long-term care services [7]. When getting older, a large majority of people prefer to be cared for at home by family or friends instead of moving into a nursing home [8, 9]. Informal care for the older people at home is mainly provided by non-cohabiting adult children [10]. The majority of caregivers are female, mostly daughters, daughters-in-law and wives [9]. In the care for the older people, female adult-child caregivers may experience additional stressors, as compared with spouse caregivers [11]. Because of their age, usually between 30 and 65, female adult-child caregivers (daughters) often experience significant life events like getting married, having children and grandchildren, being professionally active while simultaneously caring for an ageing parent. Non-cohabiting daughters report the lowest frequency of service usage, compared to cohabiting daughters, wives and other supporting relatives [12]. As daughters are an important corner stone in delivering care, it is important that their unique experiences and needs are addressed. This prompted the idea to design a qualitative study to better understand the experiences of adult daughters caring for an ageing parent. The main research question in this study is: **‘How do non-cohabiting adult daughters experience caring for their frail ageing parents who live in their own homes?’**

Methods

A phenomenological research perspective was used to better understand the daily experiences of non-cohabiting adult daughters caring for an ageing parent. Interpretative phenomenology examines the meaning people give to their lived experience of a phenomenon [13]. It describes what individuals have in common as they experience the same phenomenon [14]. The phenomenon experienced by the individuals in this study was caring for a frail ageing parent.

Participants

To be included in this study, the informal caregiver had to be an adult daughter of a frail older person living at home; non-cohabiting with the parent; living in the urban area of Antwerp and having Dutch as a mother tongue. Participants were recruited with the help from general practitioners (GPs). The GPs explained the study to their eligible patients and asked for the women's permission to be contacted by the researcher. After receiving the contact information, the researcher telephoned the women to provide additional information and make a first appointment. During this first meeting, study details were given and participants signed an informed consent form. A second appointment was made for the interview. Eleven women were interviewed.

Ethical considerations

The ethical committee of the University hospital of Antwerp approved this study (Belgian Registration Number B300201212944). Participants gave their informed consent to participate. All data were treated with respect to the participants' privacy.

Data collection

Interviews took place between March and August 2012, and lasted between one and two hours. All interviews took place at the participants' houses without the parent(s)' presence so they could speak more freely. The interviewer performed in-depth interviews with a single opening question 'Can you please tell me something about your experience with caring for your parent(s)?' Additional questions were asked to get more in-depth information about the topics brought forward by the women. The interviews ended when the women felt they had given all their relevant information.

Data analysis

Interviews were audio recorded and transcribed verbatim. NVIVO version 10 software was used to store all transcripts and facilitate data analysis. The first step in the analysis process was familiarisation with the data. The aim of interpretative phenomenological analysis (IPA) is to try to understand the content and complexity of meanings rather than to measure their frequency [15]. The transcripts were read and summarised independently by two researchers. In a second step, text fragments were coded, and after comparison between the researchers, the codes were renamed and categorised into a list of main themes.

The final main themes were (1) being a caregiver as a natural process in life; (2) the perception and consequences of caregiving activities; (3) sharing care and (4) finding a good balance between caring for an ageing parent and other responsibilities.

Results

Description of participants

Eleven women participated in this study. Table 1 shows a summarised description of the participants at the time of inclusion. All women were between 40–70 years of age. Four women were retired, five women had professional activity and two were not working for medical reasons. Eight women were married, two were divorced and one was single. All but one had children; eight of them had grandchildren. In four cases, the women took care of both parents. Five women took care of only a mother, in two cases it was only a father.

Table 1: Description of participants

Participant	Age group	Work status	Family status	Parent(s)
D1	60+	Invalidity. (used to clean houses for older people)	Married, 2 adult children, 2 grandchildren.	Father, lives alone in an apartment. Mother died one year ago.
D2	60+	Retired (used to be an educator in a home for people with mental disabilities); Does volunteer work.	Married, 1 adult daughter, 1 grandchild.	Mother, lives alone in an apartment with services for the elderly. Father died between 5 and 10 years ago.
D3	40+	Works fulltime as an accountant.	Divorced, 1 daughter who lives at home. *Co-living with her mother (no care). Parents divorced when she was young.*	Father, lives alone in an apartment with services for the elderly.
D4	50+	Works fulltime as a nurse, nightshifts on a geriatric ward.	Married, 2 adult children, 1 grandchild.	Both, parents live together in an apartment with services for the elderly.
D5	50+	Works fulltime as a home care worker for the elderly.	Married, 1 adult child (+1 son died at the age of 15), 2 grandchildren.	Mother, lives alone in an apartment. Father died 35 years ago.
D6	50+	On long-term sick leave. (a psychiatric nurse)	Single, no children.	Both parents, live together in an apartment.
D7	60+	Retired. (used to work as an administrative clerk)	Married, 2 adult children, 4 grandchildren.	Both parents, live together in an apartment.
D8	40+	Works as a music teacher.	Divorced, new relationship, 3 children who live at home.	Both parents, live together in a house.
D9	60+	Retired. (used to be a cashier in a supermarket and later a nanny)	Married, 2 adult children, 2 grandchildren.	Mother, lives alone in an apartment with services for the elderly. Father died between 5 and 10 years ago.
D10	60+	Works in the medical practitioner's practice of her husband + French teacher at home.	Married, 4 adult children, 4 grandchildren.	Mother, lives alone in a house. Father died between 5 and 10 years ago.
D11	60+	Retired. (used to help her husband in his business)	Married, 1 adult daughter, 2 grandchildren.	Mother, lives alone in an apartment. Husband died between 5 and 10 years ago.

Being a caregiver as a natural process in life

The reasons why the daughters in this study were the primary caregivers for their parents varied and were related to their individual situations. Being the only daughter (with or without brothers), being the oldest child or being the one that lives closest to the parents were the main reasons for being the primary caregiver.

> *D2: I do the most. My sister still works and my brothers . . . their contribution is more limited, a son is not like a daughter.*

The daughters felt it was their duty to take care of their parents. It was seen as a reciprocity principal, the parents looked after their children when they were young and later, when the parents were in need, children looked after their parents.

> *D8: I feel it is my duty, together with a kind of parental love. You have a bond.*

> *D1: They always took care of me when I was little, now it is my duty to give something back.*

They mentioned that they know best what their parents' values are in life and they wanted to make sure that these values are reflected in the care provided. The women felt it was their responsibility to respect their parents' wishes and make sure that others, especially professional care providers, also respect them.

> *D6: They have their peculiarities about how things need to be done, I know them.*

Most women started to take on the role of informal caregiver when an acute event took place, mostly a death of one of the parents or a hospital stay. In other cases, there was no clear starting point, but they began when they noticed a decline in the parent's mobility or capabilities. It was a gradual process; daughters did not become an informal caregiver from one day to another. A common aspect was that once they started doing things like the laundry, grocery shopping or cleaning the parent's house, they continued doing this, even when the acute situation was over.
It became a part of their daily life.

> *D9: When my father died, my mother stayed with us during the day on Monday, Tuesday and Friday . . . That company was very pleasant, for my mother as well as for the children and me. Later she kept coming over on Tuesdays. At one point I told her to bring her coloured laundry with her . . . When she became less mobile, my husband started to pick her up in the morning and bring her back home at night. It grew, step by step. I never realized it but now that I'm thinking about it, I think we do a lot for her and that is a good thing.*

> *D3: It started when my father became less mobile and experienced more difficulties carrying his groceries up the stairs to his apartment. I started to take him to the supermarket once a month for the heavy groceries and helped him to carry them upstairs. Then I made sure that there were always plenty of meals in the freezer. . . Later I noticed that he did not take his medication properly and I started to lay them out in a day-by-day medication box and checking if he had taken them. That's how it happened, one thing led to another and gradually I began to do more for him.*

The perception and consequences of caregiving activities

Table 2 shows a list of activities the women mentioned as things they do for their parents. Based on how the women expressed experiencing these activities, a division into visible and invisible activities could be made. The way they experience visible and invisible care was different. The women did not consider activities like cleaning, doing laundry and grocery shopping as difficult or unpleasant. Most of these activities were household activities that the women were used to doing in their own household. The activity itself and its result were visible: a clean house, clean clothes and a full fridge. Helping their parents with these things was seen as a lengthening of their own daily routines. However, sometimes time consuming; helping with these household activities gave them a feeling of satisfaction. They were happy that they could do something useful for their parents.

> *D9: When I finish cleaning and I say to my mother that I go back home, she smiles and I know she is happy.*

> *D2: I do not consider it a task, taking care of her. Ok, there are some less pleasant tasks but most of the time it is pleasant to do.*

Helping the parents with their personal hygiene was a visible activity that generated different feelings compared to other visible activities. This was considered as more difficult because it implied physical intimacy. Seeing your parent naked and in need of assistance for bathing or going to the toilet was not considered normal in a child–parent relationship and the women did not feel so comfortable having to do this.

> *D7: I am willing to do anything for them, but helping them with bathing, especially my father, I do not feel comfortable having to do that. . . . I do not think I will be able to do that, emotionally as well as practically. My mother maybe, but not my father.*

> *D9: In the beginning she found it difficult to accept help from a stranger (nurse) with showering, but now it is not a problem anymore. It is more difficult when I help her, which has*

> *happened occasionally. Then she is standing very cramped and feels uneasy. For me it is also very uncomfortable seeing my mother feeling constrained.*

Invisible care, in contrast to visible care, covered topics that cannot easily be considered completed or switched off in the mind. The invisible activities as reported by the women were: managing the parent's agenda, giving advice to the parent, protecting the parent, being the in-between, stimulating self-care and stimulating social contact. Opposite to visible care, the result of invisible care activities was not always very evident to other family members and professionals. Invisible care was experienced as more stressful because it was related to all the worries surrounding the well-being of their parent. The women found it very hard to put aside the invisible care; it was continuously on their minds. During the interviews, talking about the invisible activities, especially about protecting their parents, caused nonverbal emotional reactions like change in voice and even tears in some women.

In addition to managing their own household, the women became the manager of the parent's household and agenda. Planning, coordinating, making appointments, following up doctor's visits, searching for information about home services and benefits, giving information and advice and often convincing the parent about these services were experienced as very time consuming and stressful activities.

> *D8: I have to think about a lot of things, about how I am going to organize the care they need. Can I do it myself or do I need to hire a professional? Or it is about planning transportation to get them to the hospital. Or calling the physiotherapist to hear how the rehabilitation is going.*

> *D7: They got a letter from the owner of the apartment complex they live in about shared costs for the common parts of the building. Then they ask me to read it and explain to them what it is about and to give my opinion.*

Protecting the parent from certain emotional confrontations was considered as very difficult but also very important to the women. They tried to protect the parent by concealing disturbing news or minimising the parent's mental and physical deterioration. Some of the women did not seek additional help from professionals, in hopes of protecting their parent from becoming dependent on professional care providers.

> *D9: I want to keep her from worrying as much as possible. I will not tell her so easily that for instance her grandson is ill again.*

> *D7: Before they hired a cleaning lady, I brought cleaning cloths in my purse and without them knowing I cleaned the toilet seat when I came to visit because I noticed she did not clean it as often as she used to anymore.*

> *D1: Since a few weeks my mother is saying that she is forgetting a lot. Then I tell her that I forget a lot too. I laugh it away a little. On the other hand I am happy that she is going to a memory training class in the local service centre.*

Because the women were constantly trying to protect their parents from emotional burden or sadness, they found it difficult to convince their parents that they can no longer look after themselves alone, and that they are in need of professional support. They did not want to hurt the parents' feelings or confront them with their physical or mental deterioration. In everything they did, they wanted to respect the parents' wishes as much as possible. Often initially, the parents showed resistance against help from strangers. The daughters described convincing the parent to accept professional help as time consuming and difficult.

> *D7: I was sometimes ashamed when I was in their house. But telling them their house was not clean was very difficult. I did not want to hurt their feelings. After having to insist carefully for a long time, now they have a cleaning lady. At first they did not want to have a stranger working in their house but on the other hand they were not able to keep the house clean anymore by themselves.*

The daughters often stimulated their parents to remain active, go outside and have social contacts. This was also a way of protecting the parent against immobility and loneliness.

> *D2: My brothers, my sister and I take turns in the weekends to take my mother out to go and have coffee. She enjoys it. Or sometimes we bring her to our house to spend the day with us.*

> *D10: She still goes to the grocery store or the bakery by herself. Not because of the groceries, but to meet people. She is a very social person and when she does not see a familiar face for one day she gets sad. So we (brothers and sisters) feel it is our responsibility to visit her or to call her. It is like a silent agreement between us, when we know that one of us went to visit her we feel assured and do not feel the need to go there today.*

Being the protector or manager was not so visible to other family members and professionals but was very time and energy consuming for the daughters as it burdened them with a great responsibility. They did not want to let their parents down. Doing invisible activities was considered more difficult than doing visible activities, as there were a lot of emotional aspects involved.

> *D7: I find the mental part the most difficult because I have to think for them and I have to guide them and I find that difficult.*

Sharing care

The women in the study all shared at least some of their caring activities with other family members and professional care providers. Table 2 shows to what extent the daughter (D) shared the activities with others, namely family members (F) and professionals (P).

The women explained that they would try to care for their parents for as long as possible by themselves. If needed, they would initially ask for help from the family. Hiring professional care providers was usually seen as a final option.

> *D4: You know that different types of professional care exist but in fact you keep postponing engaging external help because you do not want to burden your parent with accepting help from a stranger. And then it gets to a point that the situation derails. It is difficult to decide when professional help is inevitable.*

Help from a sister or brother was experienced easiest to accept. The care shared with sisters consisted mainly of household activities. Brothers tended to have more defined tasks compared to sisters, like financial administration, handyman tasks or carrying heavy groceries. In the daughter’s opinion, brothers experienced caring for a parent in a different way compared to sisters.

> *D2: A son is different as a daughter. My brothers visit our parents every week. But doing the laundry, grocery shopping, cooking; that’s my sister and me.*

Table 2: Visible and invisible care activities

Participant	D1	D2	D3	D4	D5	D6	D7	D8	D9	D10	D11
Visible care activities											
Mail/bills	D		D		F			F	F	F	
Grocery shopping	D	F	D	F		D	D	P	F	P	
Helping with eating						D		P			
Cooking	D	F		P			F	P	F	P	
Cleaning the house	F	P	P	P	P	D	P	P	F	P	D
Helping with hygiene			P	P	P	P	P	P	P	P	P
Laying out medication			D	P	P	D	P	P	F	D	
Handyman	F	F		F	F	D	F	F	F	F	F
Gardening						D		F			
Transport	D	F		P	F	D	D	P	F	P	F
Doing laundry, ironing	D	F	F	D		D	D	D	F	P	D
Invisible care activities											
Giving advice to parent	D	D	D	D	D	D	D	D	F	D	D
Managing parent's agenda	D	D	D	D	D	D	D	D	F	D	D
Protecting	D	D	D	D	D	D	D	D	F	D	D
Being the in-between	D	D	D	D	D	D	D	D	F	D	D
Stimulating self-care	D	F	D	D	D		D	D	F	F	D
Stimulating social contact	F	D		D	D		D	D	F	F	D

White cell: no informal care provided for this activity
D: activity done by the **d**aughter (primary informal caregiver);
F: daughter gets help from other **f**amily members;
P: daughter gets help from **p**rofessional care providers

The women in this study also mentioned their own husbands as co-caregivers. The husband was often asked to help with transportation or handyman tasks. They often relied on other family members for specific task like nursing or hairdressing, depending on the relative's professional activity. The women mentioned several reasons to hand over parts of the care to a professional: the difficult combination of care giving and their own professional activity, and the high intensity of the care. Most importantly, wanting to protect the normal daughter–parent relationship was an issue that made communication about certain sensitive topics concerning care, like personal hygiene, difficult. Trusting professional care providers to help in the care for their parents was often experienced as stressful because they wanted to be sure that their parents would be treated with respect and dignity.

Therefore, even when they delegated some care to a professional, the primary caregiver remained the pivotal figure and continued coordinating care. She was the one that knew best what is going on in the parent's life and communicated with all other players, family members and professionals. Visible activities were more often shared with others than invisible activities because they were more defined, and most importantly because they did not carry as much emotional weight as the invisible activities, especially concerning the protecting activities. Notably, women who really felt supported by their family delegated more tasks to family members and professionals and also felt less of a burden. The women who experienced no or little support from others experienced more difficulties delegating care to others and had higher feeling of burden. Table 3 shows the perceived burden of the daughters and their self-reported level of feeling supported by other family members.

> *D2: I do not feel alone. I know that when I say that I do not feel well, others will take over the care for my mother.*
>
> *D3: The entire burden was put on my shoulders. One brother lives further away and my other brother's wife was ill. It is always me that has to look after our father and at one time I could not cope with it anymore. That is why I wanted him to register himself on a nursing home waiting list.*
>
> *D6: I have two brothers and a sister, but their effort is very limited. I find it very difficult to indicate to them their responsibility. In my opinion it has to come spontaneously but it doesn't.*

Table 3: Perceived burden and feeling supported

Participant	**D1**	**D2**	**D3**	**D4**	**D5**	**D6**	**D7**	**D8**	**D9**	**D10**	**D11**
Perceived burden and level of feeling supported by family											
Perceived burden	high	medium	high	medium	low	high	medium	high	no burden	medium	medium
Feeling supported by family	never	always	sometimes	always	always	never	always	sometimes	always	always	sometimes

Finding a good balance between caring for an ageing parent and other responsibilities

Caring was experienced as a constant process of seeking a balance between caring for an ageing parent and other responsibilities. The women were balancing between their own household responsibilities and family members (husband, children and grandchildren) and that of the parent. Some women had integrated the care for their parents into their daily planning.

> *D7: In the morning I take my dog for a walk and after that I go to my parents. In the afternoon I am back home to take care of my own household and everything else. But the mornings are usually for them.*

> *D1: Every morning I go to my father, together with my husband to check up on him . . . At 12 PM we go back home because my husband always works from 2 PM to 10 PM. Then I can start taking care of my own household. Actually I prefer getting up in the morning and doing my own things first but that is not possible now.*

Spending time with their husband, children and often grandchildren was very important for all women, but they did not deal with it in the same way. Some women made a clear distinction between parent time and family time, others complained they would like to spend more time with other family members or friends but did not act on it. An underlying feeling of guilt was often present.

> *D4: I spend a lot of time with my parents, but I try to avoid going there on the weekends. They know they can call me if it is necessary, but I try not to go over there. This is because my husband is at home then and I want to spend some time with him too.*

> *D1: I would like to go on a vacation with my husband but something is keeping me from going. I know my children do not mind taking over the care for my father, but are they going to do that the way I do it? No, they will rather call him to ask if everything is fine instead of going over every day.*

Discussion

This study reported an in-depth analysis of the experience of eleven daughters caring for their frail older parents. Four main themes could be identified. (1) being a caregiver as a natural process in life; (2) the perception and consequences of caregiving activities; (3) sharing care and (4) finding a good balance between caring for an ageing parent and other responsibilities.

Being a caregiver as a natural process in life

The first theme showed that caregiving was a continuous process embedded in the daily life routines of the daughters. Caring for their ageing parents is experienced as a normal part of their lives. The daughters experience the need to care for their parents as an act of reciprocity.

The perception and consequences of caregiving activities

The women expressed how they experienced caregiving activities. The reported activities could be divided into visible and invisible activities. The invisible activities, especially the activity of protecting the parent, was considered more difficult than the visible activities, as there were a lot of emotional aspects involved in the invisible activities. Being the protector was experienced as very time and energy consuming for the daughters as it burdened them with a great responsibility. They did not want to let their parents down.

Sharing care

Some visible activities were shared with others like family members and professional care providers. The women who struggled the most with the caregiving activities were those who felt alone, who experienced little support from family and friends. Having a good relationship of trust between the different caregivers and the care receiver is crucial [16]. Our results showed that the caregivers often performed management tasks and needed to negotiate with their family and the formal care providers like nurses. The daughters perceived professional care as a final option.

Finding a good balance between caring for an ageing parent and other responsibilities

The women talked about finding a good balance between caring for an ageing parent and other responsibilities. Spending time with others than the parent was experienced as very important for the women, but not often acted on. An underlying feeling of guilt towards the parent was often present.

Healthcare providers must consider the patients and the informal caregivers as competent, resourceful partners in the care process [17]. Integrated, tailored support services for informal caregivers of frail older people are needed [18]. Case management could be introduced to support informal caregivers in coordinating complex situations where formal care and informal care providers need to collaborate very intensively [19]. Primary health care professionals are well placed to identify informal caregiver needs and support informal caregivers because over time they can build a relationship of trust [20]. However, these professionals often have limited knowledge about the complete spectrum of needs of the informal caregiver, including the social and emotional implications [21].

It is important that healthcare professionals can quickly detect actual support needs. Instead of asking the general question 'How are you doing?' the professional will get a more accurate answer when asking 'How are you coping with the care for your parents?'

The implementation of an easy and quick detection tool for the need of social support could help the primary healthcare professionals to better support the informal caregiver.

The organisation of healthcare systems differs between countries. In Belgium, formal care as well as informal care is both important [8]. Informal care is funded more than in the neighbouring countries [22]. In a neighbouring country (the Netherlands), it is notable that the proportion of informal care is lower [9]. In both these countries, budgets for health care are decreasing and there is need for more efficient ways for health care supply. It is the balance of formal and informal care that will be crucial in the next decades in many developed countries with decreasing budgets for health care.

Some limitations of this study need to be addressed. Only women who had a daughter–parent relationship with the person they care for were included. This group was chosen because a large group of informal caregivers are women caring for their parents [9]. The procedure for recruiting the informal caregivers through a third party, although approved by the ethical committee, had limitations. The GP informed eligible patients and asked for their permission to be contacted by the researcher. This procedure could have led to a feeling of pressure to join the study. However, during the initial telephone conversation with the possible participants, the researcher provided more information about the study and reassured the women that they were under no obligation to take part, and that it would not affect their doctor-patient relationship. Future studies should take this issue into account when recruiting via a third party.

The women in this study were all native inhabitants of the city of Antwerp (Belgium). More research is needed on informal care in immigrants and other minority groups. It might be interesting to study these groups as they may show other coping strategies. Other mechanisms may play a role in their provision of informal care because immigrants do not use as much formal care [23].

The strength of this study is that no parent was ever present during the interviews. An inductive approach and analysing with more than one researcher both reduced the risk of influencing the researcher's interpretation of the data with previous knowledge or personal views. The importance of a safe environment and a trusting relationship between the interviewer and the participants was acknowledged.

Conclusion

This study provides more insight in the experiences of women caring for an ageing parent. Many activities of the informal caregiver are not very visible to other family members and professionals and encompass continuous activities like protecting the parent and managing the parental household. These invisible activities may be energy consuming and considered difficult because they induce emotional distress. Women can feel burdened with a great responsibility, as they do not want to let their parents down. Supporting family networks that help in both visible and invisible activities may prevent overburden. Acquiring help from formal care providers sometimes is a difficult process for the informal caregiver, as there may be pressure from the older persons to postpone this as long as possible.

Relevance to clinical practice

The women in this study felt it was their responsibility to respect their parents' wishes and make sure that others, especially professional care providers, also respect them. They experienced more stress managing invisible care activities and found this care the most difficult to share with others. Therefore, consumer-led care and the active participation of the informal caregiver in the decision-making process for building the care plan need to become more prominent. On the condition that the patient agrees, the primary healthcare professionals should systematically invite the informal caregiver to multidisciplinary care team meetings. This will make the informal caregiver feel more respected as an expert in the patient's daily care needs and improve coordination of care at home. As a result, a trusting relationship can be built between the informal caregiver and a primary healthcare professional. The informal caregivers will be less restrained to share their own needs concerning the more emotionally difficult care activities, and could also be willing to find more support if needed.

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Chapter 4

The process of accepting social support when caring for a frail older parent: a qualitative longitudinal study

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Abstract

Introduction

Many studies in the field of informal care focus on measuring the stress or burden caused by providing informal care and the effectiveness of caregiver support interventions to reduce burden and other adverse outcomes of providing informal care. Hence the positive effects of social support interventions, informal caregivers are often reluctant to accept or ask for support that could decrease their stress or burden. Therefore, the aim of this qualitative longitudinal study is to gain more insight into the informal caregiver's underlying line of thought in the process of accepting social support.

Methods

A qualitative longitudinal research (QLR) design was used to study the adult daughters' experience of caring for their frail older parents and describe their process of accepting social support.

Serial interviews (face-to-face and telephone) were conducted with each participant over the course of 1 year. Participants, appointed by the parent as their primary caretaker and not cohabiting with the parent(s), were recruited with the help from general practitioners (GP) in the urban area of Antwerp.

Results

Five elements characteristic for the process of accepting social support were identified: initial resistance, barriers, facilitators, turning points and effects on the informal caregiver.

An important personal barrier for accepting expressive social support was having difficulties in expressing their feelings, preferences and needs. Trust is also a key issue in the acceptance of both instrumental and expressive social support. Having a confidant, a person who you can turn to is an important facilitator.

Discussion

Although every participant's experience during the one year study period was unique, five common elements in the process of accepting social support could be identified. To facilitate the process of accepting social support, informal caregivers should be supported in expressing their feelings, preferences and needs better and in setting boundaries.

Key words

Social support, frail older persons, informal caregiving, longitudinal qualitative research

Introduction

While providing informal care to ageing relatives is as old as humanity, the concept knows a growing interest in policy and research in the recent years [1]. The ageing of the population, the increase of frail older people with complex care needs and staff shortages in health care put a pressure on governments and long-term care providers to search for and implement affordable alternatives for residential care for this growing group of frail elderly [2]. The shift from residential care to home care also means that the informal caregiver plays a more prominent role in daily care for the elderly [3]. Sociodemographic evolutions with more women building a professional career, later retirement, smaller families, families living further away from each other may limit the availability of informal caregivers [4, 5]. Also, it puts a pressure on those informal caregivers who do take on this role, often in combination with many other responsibilities [6].

Providing informal care to a frail older parent can be stressful at times and can have negative effects on the caregiver's health and well-being [7]. Social support is mentioned as a mediator in coping with stressful events in theoretical models of stress and coping in the context of informal caregiving [8, 9]. From a social psychological approach, Lazarus and Folkman put emphasis on the appraisal of a potential stressful situation [8]. Pearlin et al. have a sociological approach and focus on role-specific coping with stressors [9]. Perceived social support, knowing that you can rely on others, can help to appraise a situation as less stressful [10]. Also the actual receipt of social support, either instrumental or expressive social support, may alleviate the burden of providing informal care [11, 12].

Social support can be defined as "The perceived or actual instrumental and/or expressive provisions supplied by the community, social networks and confiding partners" [13]. Perceived support is the individual's subjective evaluation of the quality, adequacy and availability of support when needed. The actual (or received) support refers to objectively observable acts of support [11]. A common classification of the concept social support is the classification into structural and functional social support [11, 13]. The structural dimension of social support refers to the nature of and ties between the individual's social support systems, from close family relationships over individual social networks of family and friends to the community the person lives in. The functional dimension of social support refers to the types of support that can be provided based on their function. Functional support can be classified into instrumental and expressive social support. Instrumental support is the provision of practical help with daily household activities or care activities normally provided by the informal caregiver to the frail older parent. This can be a sibling that takes over tasks like grocery shopping or cleaning on a regular basis or during absence of the primary informal caregiver. Or it can be for example help from a nurse to assist the parent in personal hygiene. Expressive support involves psychosocial and emotional support provided by family, friends or professional caregivers in an attempt to acknowledge the informal caregiver for all the work, to support his feelings and to let him know that he is not alone. Based on the definition of Lin, social support is defined in this study as instrumental support and/or expressive support provided by family, friends or professional caregivers to the informal caregiver in an attempt to alleviate the informal caregiver's burden of caring for a frail older parent [13].

Many studies in the field of informal care focus on measuring the stress or burden caused by providing informal care [14, 15] and the effectiveness of caregiver support interventions to reduce burden and other adverse outcomes of providing informal care[12]. In Lopez Hartmann 2019 the association between perceived social support from family and friends and subjective caregiver burden was explored in the context of caring for frail older people. Informal caregivers who were unsatisfied with support from family and friends were more likely to experience burden [16]. Hence the positive effects of social support interventions, several informal caregivers are reluctant to accept or ask for support that could decrease their stress or burden [6]. **Therefore, the aim of this qualitative longitudinal study is to gain more insight into the informal caregiver's underlying line of thought in the process of accepting social support.**

Methods

Study design

A qualitative longitudinal research (QLR) design was used to study the adult daughters' experience of caring for their frail older parents and describe their process of accepting social support when confronted with age-related decline and stressor events characteristic for frailty in older people. Serial interviews (face-to-face and telephone) were conducted with each participant over the course of 1 year. The regular contact with the participants allowed to identify changes that occurred in the care situation (age-related decline and stressor events) and to get insight in how they coped with these changes in terms of accepting social support.

Data from the baseline interviews, focusing on the overall experience of caring for a frail older parent, were analyzed and reported earlier [6].

Sampling, recruitment

Women caring for a community-dwelling frail older parent were eligible to participate in the study if they were appointed by the parent as their primary caretaker and if they were not cohabiting with the parent(s). Participants were recruited with the help from general practitioners (GP) in the urban area of Antwerp. The GPs purposively selected patients that cared for a frail older parent and of whom they thought they would like to tell their story. The GP's briefly informed the women about the topic of the study and asked them for permission to be contacted by the researcher. The researcher then contacted the women by telephone to explain the study in more detail and make a first appointment for an introductory meeting. During this first meeting, the researcher and the participant had an informal conversation to get acquainted and to build up a relationship of trust, study details were given and participants signed an informed consent form. A second appointment was then made for the baseline interview. Eleven women participated in the first wave of interviews. Nine of them completed a whole year of follow-up interviews.

Data collection

Data were collected during face-to-face and telephone interviews.

Face-to-face interviews

At the start, after 6 months and after 1 year, face-to-face interviews were conducted. All face-to-face interviews (N=29) took place at the participants' houses without the parent(s) present. This allowed them to speak more freely about their parents. Interviews lasted between 1 and 2 hours each and were all conducted by the same researcher (MLH). All interviews were audio recorded and transcribed.

The focus of the follow-up interviews after 6 months and after 1 year was to go more in-depth into the changes that occurred since the last face-to-face interview and how the participants experienced social support in coping with these changes. The interview scripts for the follow-up face-to-face interviews were individually adapted based on the data gathered from the telephone interviews.

Telephone interviews

In between the face-to-face interviews, the researcher and two trained junior researchers (JW and EV) made telephone interviews to ask about changes that occurred in the past month. The opening question during the telephone interviews was always “What changed since the last time we spoke?” To guide the interview a script was used containing a list of topics and supporting questions about possible changes in health status of the parents, changes in care provision, changes in the personal life of the informal caregiver. These telephone interviews (N=79) had a mean duration of 15 minutes. The telephone interviews were audio recorded but not transcribed verbatim. The researchers who conducted the telephone interviews wrote narrative summaries of the conversations in a template they completed after each telephone interview. This template was used to individually adapt the interview scripts for the follow-up face-to-face interviews.

Table 1: data collection: number of face-to-face and telephone interviews per participant and in total

	M1	M2	M3	M4	M5	M6	M7	M8	M9	M10	M11	M12	face-to-face interviews	Telephone interviews
ICG 1	x	x	x	x	x	x	x	x	x	x	0	x	3	8
ICG 2	x	x	x	x	x	x	x	x	x	x	x	x	3	9
ICG 3	x	x	x	x	x	x	x	x	x	x	x	x	3	9
ICG 4	x	x	x	x	x	x	x	x	x	x	x	x	3	9
ICG 5	x	x	x	x	x	x	x	x	x	0	x	x	3	8
ICG 6	*x*	*x*											*1*	*1*
ICG 7	x	x	x	x	x	x	x	x	x	x	x	x	3	9
ICG 8	x	x	x	x	x	x	x	x	x	x	x	x	3	9
ICG 9	x	x	x	x	0	x	x	x	x	x	x	x	3	8
ICG 10	x	x	x	x	x	x	x	0	x	x	0	x	3	7
ICG 11	*x*	*x*	*x*										*1*	*2*
												Total	**29**	**79**

ICG: informal caregiver
M: month
0: no telephone interview possible this month
Blank: P6 and P11 decided not to participate anymore. Therefore they are not included in the longitudinal analysis.

Data analysis and management

All transcripts from the 3 waves of face-to-face interviews were uploaded as separate files in QSR NVivo 10 software to facilitate data analysis. The titles of the files contained the participants code and the number of time wave. This helped to identify the time wave for which the data were coded for each participant.

Since the aim of the study is to study individual experiences and describe the process of accepting social support, data were analysed using a trajectory approach [17]. Trajectory analysis emphasizes individual trajectories and is applicable when the research interest is the reaction of an individual or small group of individuals to an experience or process that can change over time [17]. Data analysis for this longitudinal research question started when all data were collected after the last wave of interviews. This allowed to code case per case across time waves to maintain the focus on the participant's story as a whole.

Coding of the data was done independently by the main researcher (MLH) and either JW or EV who divided the transcripts between them. After coding the first 2 entire cases (all transcripts from the same participant), codes were compared and discussed between the researchers.

When all transcripts were coded, the researchers (MLH, JW and EV) compared and discussed their codes. The codes were renamed if needed and grouped into themes.

Additionally, an external informal caregiver (not a participant) coded the transcripts indicating the changes (age-related decline and stressor events) she felt were important to have an impact on accepting social support from her point of view as an informal caregiver. The coding from the external informal caregiver were used during the discussions in the analysis phase to understand the findings from the point of view of the participants.

Ethics

The ethical committee of the University hospital of Antwerp approved this study (Belgian Registration Number B300201212944). Participants gave their written informed consent to participate at the start of the study. All data were treated with respect to the participants' privacy. There was no treatment or other relationship between participants and the research team.

Quality and reporting

The COREQ checklist for reporting qualitative research and SmithBattle et al's recommendations for qualitative longitudinal research (QLR) are used to enhance the quality and reporting of this study [18, 19].

Results

Participants

Nine out of the eleven women that were included at the start of the study, completed the entire study year and were included in this longitudinal analysis. A description of the nine participants included in the longitudinal analysis is summarized in table 2. They are referred to further as ICG A,ICG B, ICG C…. More details on all participants, including the two participants that dropped out during the course of the study year, are reported earlier [6].

All women were between 40 and 70 years of age. Five women had a professional activity, three women were retired and one was not working for medical reasons. Seven women were married, one was divorced but in a new relationship and one was single. All woman had children; seven of them had grandchildren. Notwithstanding that others were also involved in the care for the frail older parent(s), the women were appointed to by the parent as being their primary informal caregiver. Three women took care of both parents. Four women took care of only a mother, in two cases it was only a father. Altogether, the nine women cared for a total of twelve parents.

Table 2: description of participants

ICG (N=9)	Age	Professional activity	Family (core)	Parents (N=12)
A	60+	Invalidity	Husband 2 adult children 2 grandchildren	**Father** *Mother died 1 year ago*
B	60+	Retired	Husband 1 adult daughter 1 grandchild	**Mother** *Father died between 5 and 10 years ago*
C	40+	Works fulltime	No partner 1 adult child	**Father** *Mother is alive (not frail), parents divorced*
D	50+	Works fulltime	Husband 2 adult children 1 grandchild	**Both parents**
E	50+	Works fulltime	Husband 1 adult child 2 grandchildren	**Mother** *Father died 35 years ago*
F	60+	Retired	Husband 2 adult children 4 grandchildren	**Both parents**
G	40+	Works part-time	Partner 3 adolescent children	**Both parents**
H	60+	Retired	Husband 2 adult children 2 grandchildren	**Mother** *Father died between 5 and 10 years ago*
I	60+	Works part-time	Husband 4 adult children 4 grandchildren	**Mother** *Father died between 5 and 10 years ago*

ICG: informal caregiver
Parents: in bold are the parents being cared for by the ICG

The process of accepting social support

The analysis of the longitudinal interview data resulted in themes that describe five common elements in the process of accepting social support: (1) Initial resistance, (2) barriers, (3) facilitators, (4) turning points and (5) effects of accepting support. These elements will be explained and illustrated with cases and quotes in this result section.

Before elaborating on the elements separately, the following set of quotes from one participant's individual trajectory illustrates the entirety of the process of accepting social support in the care for her frail older parents.

Table 3: set of quotes illustrating the process of accepting social support

"You know that different types of support exist but in fact you keep postponing engaging external help. You don't want to burden them [parents] with accepting strangers in their home. And then it gets to a point that the situation derails, too much. It is difficult to know when professional help is inevitable. You keep on going." [ICG D, time T6]

…

"He told me that I should think about myself, that I can't ignore myself. My husband tells me the same." [ICG D, time T12]

…

"Now, with this home care nurse, now every day someone visits them, and I feel more reassured. I have to admit, in the beginning I felt strange and guilty even that I didn't visit them myself anymore every day but every two days now. But it is better. I should have done it sooner actually." [ICG D, time T12]

This example set of quotes above contains all five elements in the process of accepting social support that could also be identified in the stories told by the other participants and will be discussed further in this result section.

In this example the daughter is **initially reluctant** to engage professional caregivers because she wants to protect her parents. This protective attitude towards her parents is a **barrier** to accepting support. An accumulation of stressors and stressor events, common when caring for frail older persons, leads to a point where the daughter is confronted with a 'derailed situation'. The **turning point** in the process of accepting social support is when she becomes aware of the seriousness of the situation through a spontaneous conversation with a health professional where he tells her something her husband also tells her. The fact that she knows about possible support to engage is a **facilitator** in the acceptance of social support. After she eventually accepts to share the care with a home care nurse, she states that she should have done this much sooner. This **effect** being a positive experience can function as a facilitator when confronted with similar situations in the future.

Initial resistance to accept social support

The initial resistance to accept social support is often not expressed and therefore not always visible to others. There were moments where the participants in this study did express initial resistance to accept social support that was proposed by others right away. But in most cases the initial resistance was mentioned only when the women were talking in retrospect about their situations. Initial resistance was expressed by using statements or short sentences that block further conversation on the topic like “I don’t need help”, “I’m fine, everything under control”, “I don’t want to be a burden”, “No one can help me, I have to figure it out myself”. These statements were often used in an initial phase of the process of accepting social support and are linked to the barriers.

Barriers in the acceptance of social support

The women in the study encountered various barriers in accepting social support. These barriers could be towards accepting instrumental and expressive social support. Personal as well as external barriers could be identified. Personal barriers are a reflection of one’s feelings, competences, personality while external barriers are linked to relationships with others and previous experiences.

Table 4: barriers hindering the acceptance of social support

	Personal barriers	**External barriers**
Instrumental support	• Wants to keep control • Prefers to do it herself • Thinks it is easier to do it herself • Feels it is her duty to care for her parents	• Has made a promise to care for parent • Wants to protect parents • Wants to protect others (siblings) • Has other view than siblings on what is best for parents • Has previous negative experience with professionals • Has trust issues
Expressive support	• Is not able to express feelings well • Is not able to express what she wants or needs • Feels ashamed about her feelings	• Doesn’t want to burden others with her problems • Has a bad relationship with siblings • Feels she has no one to turn to • Has trust issues • Has previous experience with gossip by co-worker/friend

Barriers for accepting instrumental social support

Instrumental social support can be help from family and friends or professional caregivers in the daily care for the frail older parent. The most frequently mentioned personal barriers keeping the informal caregivers from accepting instrumental social support are: wanting to keep control over the situation, a preference to do something themselves, feeling it is their duty to care for the parent, thinking it to be easier to do it themselves instead of explaining it to someone else.

Besides the personal barriers, a lot of barriers had to do with the informal caregiver's relationship to others (external barriers). In first place with the parents. There were woman that made a promise to their parents that they would take care of them and they didn't want to break that promise by delegating care to others. Apart from the fact that they made a promise or not, all women mentioned that they wanted to protect their parents. Generally, support from siblings or other close family members was accepted easier than support from professionals. There were 2 main reasons not to ask or accept support from siblings. One was that the women wanted to protect a sibling because in her opinion the sibling had already enough on his/her mind. A second reason was that in some cases the siblings had different ideas on what is best for the parent(s). The most frequent mentioned barriers for accepting support from professionals had to do with negative past experiences and trust issues, potentially linked to each other.

Barriers for accepting expressive social support

For accepting expressive social support some other barriers were identified than for accepting instrumental social support. Expressive social support can be a loving hug, but often it implies a conversation about feelings. And especially when women struggled to express their feelings or needs they found it difficult to accept expressive social support. Feeling ashamed was also mentioned as a personal barrier. They felt shame about their anger and frustration towards their parents sometimes. Some women didn't want to burden others with their problems and that kept them from opening up to receiving social support. An important barrier for accepting expressive social support was related to the quality of the relationship between the informal caregiver and possible providers of expressive social support. Barriers were: a bad relationship with siblings (or other relatives), feeling that she has no one to turn to and trust issues because of negative past experiences. One woman mentioned opening up to a co-worker/friend she trusted and finding out that she had talked about their conversation behind her back to others.

Facilitators in the acceptance of social support

Some facilitators could be identified, either personal or external, that helped the women during the process of accepting social support.

Table 5: facilitators in the acceptance of social support

	Personal facilitators	External facilitators
Instrumental support	• Is able to set boundaries	• Has good agreements between siblings about care tasks • There are family meetings • Has professional caregivers in own personal network (family, friends, friends of friends)
Expressive support	• Is able to express feelings • Feels that she is not alone	• Has a confidant • Has trust in the people that provide support • Has a good relationship with siblings • Has previous positive experiences with receiving support

Facilitators for accepting instrumental social support

Being able to set boundaries in providing care and communicating about them was a clear facilitator for many women in accepting instrumental support. Depending on the situation and the personality of the woman, setting boundaries was not always easy. Setting boundaries is knowing what you are willing to do in the care for your parents and knowing when or for which activities you need support. Something almost all woman agreed on was that they didn't want to assist their parents when they needed daily assistance in personal hygiene. When this care need emerged, accepting support was not very difficult.

Good relationships and clear agreements or task division between siblings were strong facilitators. In some families family conference meetings were organized when the parent's care needs increased or in crisis situations. In other families the siblings who had a good relationship with each other had frequent informal discussions about the care for the parents. When professional caregivers needed to be hired, they preferred to contact people they already knew personally or professionally or were recommended by family and friends.

Facilitators for accepting expressive social support

Being good in expressing your feelings helped to be open up to receiving expressive social support. Feeling that you are not alone was important and made it easier to accept social support. Good relationships with family and friends, strong family ties, trusting relationships were important facilitators in accepting expressive social support. Most women had a confidant, a person that was their main source of expressive social support. In many cases it was the husband, but for some woman it was also their sister.

Turning points in the process of accepting support

Small progresses in accepting social support happened unconsciously. And it is only after a while that they noticed they gradually received more support, instrumental and/or expressive. Besides the small progresses, for some of the women some clear turning points could be identified in the process of accepting social support. These women were confronted with an accumulation of stressor events and became aware of the seriousness of the situation and their support needs. Some turning points in accepting social support are described in the example case illustrations below.

Spontaneous advice from a health professional, reinforced by husband

Two women described a similar turning point where they both were spontaneously approached by a health professional who initiated a conversation about self-care.

Case illustration 1

One woman was visiting her parent in the hospital and told him she fell at home because she was feeling dizzy. A nurse overheard her talking to her parent and asked to speak with her. The nurse advised the woman to also think about her own health and not only the care for the parent and made suggestions to help the woman to take some time for herself. The nurse suggested that instead of visiting the parent every day from 2PM until 7.30PM as she normally did, to come a little later and first take some time for herself to rest or do something else. At home, the woman told her husband and he agreed with the nurse, stimulating her to try the nurses suggestion. In a follow-up interview the woman tells that she followed the nurses advise and shortened her visits to be able to take some time for herself and that it gave a good feeling. Unfortunately this good feeling was temporary. A new set back in the health of the parent caused the woman to take on even more care than before and giving up on her me-time.

In this case the reinforcement of the husband who agreed with the nurse’s suggestion was decisive for the woman to accept the expressive social support (advise) offered by the nurse.

Case illustration 2

One woman was in physiotherapy for back problems. During the sessions she told a few things about her care for her parents. The physiotherapist told her that self-care is important, not only for her back problems but also for her mental health. Apparently her husband also had told her already to think about herself and set boundaries in the care for the parents. She started to make some changes in her care routine so that she didn't have to go to the parents daily anymore. Since this turning point she also started to accept more instrumental social support, like help from a home care nurse, that she was postponing. In a follow-up interview she told that in the end she was happy that she made the decision to do less of the care herself. She admits that initially she felt guilt towards her parents for choosing herself over them and hiring a stranger to care for them. But when she saw that the parents accepted the nurse, the guilt disappeared and she even regretted that she didn't start to share the care sooner.

In this case it was, similar to the previous case, also the fact that both her husband and the physiotherapist advised her similar things that convinced her to accept this support/advise.

Repetition in offering support or reinforcement to accept support from more than one trusted person will lower the threshold for the informal caregiver, convincing her to accept support.

Family conference meeting

For one woman having a family conference meeting with all siblings and the mother present was a turning point in accepting (instrumental) social support.

Case illustration 3

The mother of ICG I has a heart condition. After a medical check-up the medication changed and for a while the doses needed to be adapted daily based on lab results. Since then ICG I visited her mother more often to adjust the medication doses. About this she says: “I don’t know how I am going to sustain this.” At the same time she says that both her sister and the home care nurse offered to help with the daily medication adjustments. But she rejects this help saying “It is easier if I do it myself. My husband is the general practitioner and he receives the lab results. So I know it first. If my sister or the nurse have to do the adjustments, I still have to communicate with them about the lab results to make the adjustments.”

Because of the change in medication, the mother also had to go to the bathroom more frequently at night. A combination of more frequent nightly bathroom visits and mobility problems caused the mother to fall a few times. These nightly falls came to the attention of the other siblings. And one sibling initiated a family meeting to discuss the growing care needs of the mother. Initially ICG I was not enthusiastic about a family meeting to discuss the care needs. She was afraid that she had to give up control over the care for her mother. They held a family meeting with all siblings and the mother present. During the meeting they decided together that extra professional help from the nurse and home care assistants should be installed.

During a follow-up interview later that year ICG I stated that she felt more reassured now that there is someone with the mother every day to keep an eye on her.

Despite the initial reluctance from ICG I to have the family meeting, it resulted in her feeling reassured about not having to go to her mother on a daily basis. The fact that during the family meeting there was an open communication, all siblings agreed on what needed to be done in agreement with the parent, convinced ICG I to accept the fact that engaging more professional help was now necessary and acceptable.

Effects of accepting support on the informal caregiver

After accepting social support, the women expressed mainly positive effects of the support in reducing the emotional burden: “I feel more reassured”, “I feel less ashamed”, “I feel better”, “I should have done this sooner”. Positive experiences with accepting social support can serve as a facilitator in future similar situations.

Discussion

Main results

The aim of this qualitative longitudinal study was to describe the process of accepting social support when caring for a frail older parent. Although every participant's experience during the one year study period was unique, similarities in the process of accepting social support could be identified. Five elements are central in this process: initial resistance, barriers, facilitators, turning points and effect of accepting support.

Barriers and facilitators for accepting social support

Personal barriers and facilitators are linked to one's feelings, competences, personality while external barriers and facilitators are linked to relationships with others and previous experiences.

Personal barriers and facilitators

The two most important personal facilitators were being able to set boundaries for themselves and being able to express their feelings. These two personal facilitators mirror two important personal barriers; wanting to keep control and not being able to express feelings. An important personal barrier for accepting expressive social support was having difficulties expressing their feelings, preferences and needs. The women who experienced this as a barrier formulated two main reasons for it to be difficult. For some it was difficult to express their feelings and thoughts because they felt chaos in their head. Some women said they didn't know the correct words that matched their feelings and that they didn't know how to explain how they felt to others who are not in their situation. The women included in this study were all women without a migration background. It is likely to believe that not being able to express feelings would be an even larger barrier for informal caregivers from ethnic minority groups. Culture and language have an impact on expressing feelings and accepting support [20].

Being able to set boundaries facilitates the process of accepting support. The women who knew what was within or beyond their own possibilities and were willing to admit that, had less difficulties accepting instrumental social support for those activities they felt not capable of. In contrast, women who preferred to keep control over all caregiving activities, even if the level of care passed beyond their own capabilities, often struggled to accept support. Learning how to set boundaries for themselves could help those women who prefer to keep control in their process of accepting social support.

External barriers and facilitators

The women mentioned external barriers and external facilitators that are linked to the informal caregiver's relationship to others and past experiences. Support from family and friends, especially siblings, is generally easier to accept than support from professional caregivers under the condition that there is a good relationship between the siblings or other relatives. Arguments between siblings or different opinions on what is best for the parent can serve as a barrier. Past experiences are mentioned as having an influence on accepting support or not. Positive experiences with social support will make it easier to accept social support in the future. This applies to both the acceptance of instrumental and expressive support. Negative experiences will serve as an important barrier. Negative past experiences are frequently related to trust issues. Trust is an important issue in the acceptance of both instrumental and expressive social support. Having a confidant, a person who you can turn to is an important facilitator. In most cases it was a husband or a sister.

An Australian study examining why informal caregivers of frail older people are not using available respite services found that concerns regarding trustworthiness and quality of support from others including both family and formal support services held the informal caregivers from accepting respite care [21]. This is in line with the barriers that emerged in our study.

Turning points

Accepting social support is a dynamic process where positive and negative arguments for accepting social support, barriers and facilitators, are constantly weighed unwittingly. We could identify some turning points in the women's stories were they became aware of the seriousness of the situation and their support need. Unfortunately situations often have to derail before being noticed.

One thing the different stories had in common was the fact that other people initiated the conversation about how the informal caregivers were coping that led to a turning point in the acceptance process. It was interesting to hear two similar experiences where in both cases a health professional spontaneously initiated a conversation with the informal caregiver about self-care and in both cases the woman mentioned the fact that their husband confirmed what the health professional said as being decisive for accepting social support and making changes. These findings point at a possible important role for the health professionals and confidants in helping the informal caregiver to become aware of the seriousness of the situation leading to turning points in the process of accepting support and to actively ask them at different stages how they are coping.

Methodology

A qualitative longitudinal research (QLR) design was used in this study. Although the method is time consuming, the benefits are well worth achieving [22, 23]. This method allowed to see an evolution in the participant's process of accepting social support. Interviewing a group of participants every month for an entire year resulted in a lot of chronological data. A structured approach in data collection and data storage helped in the analysis of the data [17, 23].

Nine out of the eleven participants remained in the study the entire year. The targeted selection of participants by the GP's, the informal introductory visit from the researcher and the regular telephone contact contributed to the low attrition [24]. The two women who decided to stop participating in the course of the follow-up were contacted a final time by telephone to ask for their motivation to quit and to ask permission to use the data already collected.

The advantage of the regular short telephone interviews was that small changes were still fresh in the participant's memory [24]. Another advantage was that the regular contact facilitated the relationship between participants and research team. It should be noted that despite the advantages, the monthly phone calls and interviews could have had a therapeutic effect on the informal caregiver [24]. Telling their story and reflecting on the care they provide and the support they receive could have had an accelerating effect on their process of accepting social support.

Conclusion

The aim of this study was to describe the informal caregiver's process of accepting social support when caring for a frail older parent. The qualitative longitudinal design allowed to document changes over time, making it possible to identify five elements characteristic for the process of accepting social support: initial resistance, barriers, facilitators, turning points and effects of accepting support. To facilitate the process of accepting social support, informal caregivers should be supported in expressing their feelings, preferences and needs better and in setting boundaries.

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Chapter 5

Caring for a frail older person: The association between informal caregiver burden and being unsatisfied with support from family and friends

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Abstract

Introduction

Although informal caregivers (ICG) find caring for a relative mainly satisfying, it can be difficult at times and it can lead to a state of subjective burden characterized by -among others- fatigue and stress. The objective of this study is to analyse the relationship between perceived social support and subjective burden in providing informal care to frail older people.

Methods

A descriptive cross-sectional study was conducted using data from a large nationwide longitudinal effectiveness study. Pearson correlations were calculated between the variables for support and burden. Logistic regression models were applied to determine the association between being unsatisfied with support and burden, taking into account multiple confounding variables.

Results

Of the 13229 frail older people included in this study, 85.9% (N=11363) had at least one informal caregiver. Almost 60% of the primary informal caregivers manifested subjective burden, measured with the 12-item Zarit-Burden-Interview (ZBI-12). The percentage of informal caregivers that were unsatisfied with support from family and friends was on average 11.5%. Logistic regression analysis showed that being unsatisfied with support is associated with burden (OR1.85; 95%CI1.53–2.23). These results were consistent for the three groups of impairment level of the frail older persons analysed.

Discussion

The association between perceived social support and subjective caregiver burden was explored in the context of caring for frail older people. ICGs who were unsatisfied with support were more likely to experience burden. Our findings underline the importance of perceived social support in relation to caregiver burden reduction. Therefore efforts to improve perceived social support are worth evaluating.

Key words

informal caregivers, frail older people, caregiver burden, social support

Introduction

The increasing number of frail older people is a worldwide concern as it may threaten the sustainability of public health care systems [1]. Although healthy ageing and keeping elderly persons active has been proposed as a concept that may help to decrease this risk, measures are needed to cope with the increasing care demands of this frail older population [1]. When in need of care, many frail older people prefer to stay in their homes [2]. The proportion of non-institutionalised people over the age of 65 receiving informal care in Europe is on average 29% and increases with age; the average for people aged 80 years and older is 47.5%[3]. Informal care is mainly provided by relatives, especially spouses and adult children [4]. The majority of these caregivers are female, mostly daughters, daughters-in-law and wives [2].

While many informal caregivers (ICG) report positive attitudes towards caring, it can also be challenging and may cause the ICG to experience physical and mental health problems [5], financial problems and social isolation [6]. A negative appraisal of the caregiving situation by the ICG can lead to a state of subjective burden characterized by -among others- fatigue and stress [7]. Several contextual factors can contribute to perceived caregiver burden. These encompass the level of dependency on the frail older person, presence of cognitive or behavioural problems of the frail older person, the number of hours spent by the ICG providing care and living with the frail older person [8].

Studies on social support in the context of informal caregiving show positive effects of social support on psychological outcomes like subjective burden [7, 9-11]. In a recent comprehensive meta-analysis, del Pino Casado et al (2018) studied the association between social support and burden in caregivers of adults and older adults. They highlight that especially perceived social support is more related to subjective burden than received social support. Perceived and received social support both look at the functional dimension of social support (emotional, instrumental and informational). The difference lies in the fact that perceived social support measures satisfaction, adequacy and availability of support, whereas received social support measures frequency of support [7]. Nevertheless, del Pino Casado et al (2018) also acknowledge the mixed findings in the literature on the relationship between social support and caregiver burden. Taken into account that in their meta-analysis all adults (18 years old and more) were included, the question remains if the findings can be transferred to the frail older population.

The large number of participants in this study and focus on solely the frail older population provides the opportunity to contribute to the evidence already established by among others del Pino Casado et al (2018), but focused on informal caregivers of frail older people with low, mild and moderate to severe impairment levels.

Consequently, the objective of this study is to analyse the association between informal caregiver's subjective burden and perceived social support in providing informal care to frail older people. Additionally, potential differences in association between burden and social support according to level of impairment of the frail older people will be studied.

Methods

Context

This is a nested descriptive cross-sectional study in a larger nationwide longitudinal effectiveness study (Protocol 3) that evaluates innovative interventions to delay institutionalization of frail older persons, maintain or improve their functional status and their quality of life while assessing the cost of staying at home and the impact on the burden of their main ICG. The protocol of this effectiveness study was previously published [12].

Participants

People aged 65 years or older were eligible to be included in the study if they were frail. Frailty was measured either with a score of 6 or more on the Edmonton Frailty Scale [13], needing assistance on the Belgian version of the Katz dependency scale [14] or having a dementia diagnosis. A frail older person experiences losses in one or more domains of physical, psychological and social functioning and this may result in an increase of the risk of adverse outcomes [15]. Presence of an ICG was questioned in the InterRAI-HC as "Are there informal caregivers available and what is their relationship with the older person?". The primary informal caregiver was, according to the older person, the person who helps him/her the most or whom he/she can rely on most. It could be a spouse, another family member, friend or neighbour but not a paid care provider [16].

Data collection

At inclusion in the study, described in de Almeida Mello et al(2012), a global assessment of the frail older person was made using the interRAI-HC instrument [12]. The interRAI-HC instrument is a comprehensive assessment to map the needs and the care context of the person being cared for. The outcomes from the instrument have been internationally validated in comparison with gold standard measures [17-21].

ICGs filled out the 12-item Zarit-Burden-Interview (ZBI-12) to assess the level of caregiver burden [22]. The cost of living at home, including time spent caring and use of formal care and support services was assessed by an ad-hoc economic questionnaire made for this study [23].

Variables used in the analysis

The variable ‘feeling supported’ was measured with an item from the interRAI-HC instrument, which assesses whether or not the primary ICG was unsatisfied with the support received from family and friends. The answer could be either ‘yes’ or ‘no’. Caregiver burden was measured with the ZBI-12 [22]. Caregivers rated their self-perceived burden on a 5-point Likert scale where 0=never and 4=nearly always, and scores ranged from 0 to 48 with a score of 10 indicating burden and a score of 17 or more indicating clinically significant (high) burden [24].

The level of impairment of the frail older person was defined as a composite score. Stratification was made between low, mild and moderate to severely impaired older persons using their scores on the Activities of Daily Living Scale (ADL) (range0-6), Instrumental Activities of Daily Living Performance Scale (IADLP) (range0-48) and the Cognitive Performance Scale (CPS) (range0-6) in the interRAI-HC instrument.

- Low impairment: low IADLP (IADLP score<24), low ADL (ADL score<3) and low cognitive impairment (CPS score<3)
- Mild impairment: high IADLP (IADLP score >=24), low ADL (ADL score<3) and low cognitive impairment (CPS score<3)
- Moderate to severe impairment: high IADLP impairment (IADLP score >=24) and high ADL or cognitive impairment (ADLH score>=3 or CPS score>=3)

Statistical analysis

The Chi square test was used to determine the differences in characteristics among the ICG such as cohabitation and relationship with the frail older person. ANOVA tests were performed to analyse the differences between the subgroups of people for age and scores on the scales for ADL, IADLP, CPS and the Depression Rating Scale (DRS, range 0-14).

Pearson correlations were calculated to determine the pairwise correlation coefficients between the dichotomous variables for feeling supported and for burden. Univariate and multivariate logistic regression models were applied to calculate the association between unsatisfied with support and burden, taking into account the confounding variables; measured using items of interRAI-HC; age of the ICG (continuous), cohabitation (yes/no), presence of behaviour problems (6 items), ADL score (4 items), IADLP score (8 items), CPS score (5 items) and DRSscore (7 items)[17]. The odds of burden was expressed in odds ratio (OR) with a 95% confidence interval (CI). All analyses were performed using Stata/IC11.1. A probability value of <0.05 was considered significant.

Ethics

This study was approved by the Belgian Privacy Commission and by the Ethics committee of the Belgian Universities involved (B40320108337).

Results

Description of the population

Out of the 13229 frail older people included in the study, 85.9% (N=11363) had at least one ICG, and 42.3% also had a secondary ICG. The primary ICG was mainly an adult child (56.5%) or a spouse (29.3%). Almost 60% of the primary ICG (58.6%) had a score of 10 or more on the ZBI-12scale, meaning that they experienced burden (ZBI-12≥10). The percentage of ICG with high burden (ZBI-12≥17) was 28.4%. The proportion of ICG with burden increased with impairment level: 41.9% in the low impaired group, 55.2% in the mildly impaired group and 62.7% in the moderate to severely impaired group. Almost one out of five ICGs (18.8%) expressed feelings of sadness, anger or depression. A third of all ICGs (33.2%) felt unable to maintain to function as an informal caregiver. The percentage of ICG that was unsatisfied with the support they received from family and friends was on average 11.5%, and was the highest in the moderate to severely impaired group (12.9%).

Table 1: Description of the population; frail older people and primary informal caregivers. Stratification by impairment level of the frail older people.

Frail older people with at least one informal caregiver (ICG)	Total (N= 13229)	Low impaired (N=2142)	Mildly impaired (N=2770)	Moderately to severely impaired (N=8317)
Gender (female)	68.6%	70.2%	74.3%	65.9%
Age (median)	82	80	82	82
ADL score (0-6) (median)	3	0	2	3
IADLP score (0-48) (median)	34	15	32	38
CPS score (0-6) (median)	1	0	0	2
DRSscore (0-14) (median)	1	1	0	1
% having behaviour problems	12.5%	5.2%	4.6%	17.4%
% having depression (DRSscore≥3)	29.9%	29.7%	22.0%	32.5%
% having primary ICG	85.9%	61.8%	84.8%	87.6%
% having secondary ICG	42.3%	25.6%	46.0%	44.6%
Primary informal caregiver	N= 11363 (85.9%)	N=1323 (61.8%)	N=2350 (84.8%)	N=7288 (87.6%)
Age (median)	59	57	57	62
Relationship to frail older person				
Adult child	56.5%	62.2%	68.0%	51.5%
Spouse	29.3%	18.6%	17.2%	35.6%
Sibling	3.7%	4.9%	4.1%	3.3%
Other relative	5.1%	6.0%	5.1%	4.8%
Other	5.5%	8.3%	5.6%	4.8%
% living with frail older person	38.5%	22.4%	23.7%	46.8%
% with feelings of sadness. anger, depression	18.8%	12.8%	11.1%	22.5%
% unable to maintain as caregiver	33.2%	33.6%	27.3%	33.7%
% unsatisfied with support by family and friends	11.5%	8.4%	8.7%	12.9%
Primary informal caregiver filled out the ZBI-12	N=8619 (75.9%)	N=997 (75.4%)	N=1867 (79.4%)	N=5755 (79.0%)
% with burden on ZBI-12scale:				
ZBI-12score≥10 (burden)	58.6%	41.9%	55.2%	62.7%
ZBI-12score≥17 (high burden)	28.4%	16.9%	21.4%	33.0%

ADL: Activities of Daily Living
IADLP: Instrumental Activities of Daily Living Performance
CPS: Cognitive Performance Scale
DRS: Depression Rating Scale
Behaviour problems: Variable to indicate the presence of behaviour problems (daily or less than daily).
ZBI-12: Zarit Burden Interview, 12-item version.

Association between being unsatisfied with support by family and friends and perceived burden.

A weak but significantly positive correlation was found between perceived burden (ZBI-12>10) and feeling unsatisfied as an ICG with the support received from family and friends (r=0.1373, p<0,001). There was also a weak but significantly positive correlation between perceived high burden (ZBI-12>17) and feeling unsatisfied as an ICG with the support received from family and friends (r=0.1907, p<0.001).

Table 2 shows the multivariable logistic regression analysis to explain the association between being unsatisfied with support by family and friends and perceived burden/high burden. Analyses for the total group of ICG and the three subgroups per frail older persons' impairment levels were performed taking into account the confounding variables age of the ICG, cohabitation, presence of behaviour problems, ADL score, IADLP score, CPS score and DRSscore. Out of a total of 11363 ICG, data of 6442 ICG could be included in the logistic regression analysis. ICG not included in the analysis either did not have a complete ZBI-12 (N=2744) or had at least 1 other necessary item missing (N=2177). Additional analysis of the characteristics of ICG with (N=8619) and without complete ZBI-12 (N=2744) showed no significant differences.

Table 2: Logistic regression analysis of the association between burden / high burden and being unsatisfied with support from family and friends: analysis on the total population and on subgroups.

ALL primary informal caregivers (N= 6442)									
ICG with burden (ZBI-12≥10)					ICG with high burden (ZBI-12≥17)				
	OR	95% CI		P-value		OR	95% CI		P-value
Unsatisfied with support	**1.85***	**1.53**	**2.23**	**<0.001**	**Unsatisfied with support**	**1.97***	**1.67**	**2.33**	**<0.001**
Living together	1.25*	1.10	1.43	0.001	Living together	1.48*	1.29	1.70	<0.001
CPS score	1.13*	1.09	1.17	<0.001	CPS score	1.18*	1.14	1.23	<0.001
ADL score	1.03*	1.00	1.07	0.049	ADL score	0.98	0.94	1.02	0.266
DRS score	1.12*	1.10	1.15	<0.001	DRS score	1.13*	1.10	1.16	<0.001
Age ICG	0.99*	0.98	0.99	<0.001	Age ICG	0.99*	0.98	0.99	<0.001
Behaviour	1.55*	1.37	1.75	<0.001	Behaviour	1.45*	1.33	1.63	<0.001
A probability value of <0.05 was considered significant and indicated with * next to the OR									

Table 3 (continued): Logistic regression analysis of the association between burden / high burden and being unsatisfied with support from family and friends: analysis on the total population and on subgroups.

Informal caregivers of LOW IMPAIRED older people (N=706)									
ICG with burden (ZBI-12≥10)					ICG with high burden (ZBI-12≥17)				
	OR	95% CI		P-value		OR	95% CI		P-value
Unsatisfied with support	**2.54***	**1.42**	**4.54**	**0.002**	**Unsatisfied with support**	**2.66***	**1.44**	**4.89**	**0.002**
Living together	1.41	0.94	2.13	0.098	Living together	1.32	0.78	2.23	0.301
CPS score	1.12	0.89	1.41	0.343	CPS score	1.33	0.99	1.77	0.052
ADLH score	0.95	0.78	1.15	0.577	ADLH score	1.03	0.79	1.34	0.833
DRS score	1.16*	1.08	1.24	<0.001	DRS score	1.11*	1.03	1.20	0.009
Age ICG	0.98*	0.96	0.99	<0.001	Age ICG	0.97*	0.95	0.99	0.001
Behaviour	1.53	0.94	2.46	0.084	Behaviour	1.52	0.95	2.43	0.080
A probability value of <0.05 was considered significant and indicated with * next to the OR									
Informal caregivers of MILDLY IMPAIRED older people (N=1505)									
ICG with burden (ZBI-12≥10)					ICG with high burden (ZBI-12≥17)				
	OR	95% CI		P-value		OR	95% CI		P-value
Unsatisfied with support	**1.61***	**1.06**	**2.44**	**0.025**	**Unsatisfied with support**	**2.55***	**1.70**	**3.82**	**<0.001**
Living together	1.09	0.83	1.44	0.539	Living together	1.49*	1.08	2.06	0.016
CPS score	1.20*	1.04	1.37	0.010	CPS score	1.37*	1.16	1.60	<0.001
ADL score	1.18*	1.05	1.33	0.007	ADL score	0.94	0.81	1.09	0.404
DRS score	1.09*	1.03	1.15	0.004	DRS score	1.13*	1.07	1.20	<0.001
Age ICG	1.00	0.99	1.01	0.588	Age ICG	0.99	0.98	1.00	0.210
Behaviour	1.44	0.96	2.16	0.082	Behaviour	2.42*	1.64	3.57	<0.001
A probability value of <0.05 was considered significant and indicated with * next to the OR									
Informal caregivers of **MODERATELY TO SEVERELY IMPAIRED older people (N=4231)**									
ICG with burden (ZBI-12≥10)					ICG with high burden (ZBI-12≥17)				
	OR	95% CI		P-value		OR	95% CI		P-value
Unsatisfied with support	**1.86***	**1.48**	**2.33**	**<0.001**	**Unsatisfied with support**	**1.79***	**1.48**	**2.17**	**<0.001**
Living together	1.35*	1.15	1.58	<0.001	Living together	1.51*	1.28	1.77	<0.001
CPS score	1.11*	1.07	1.16	<0.001	CPS score	1.13*	1.09	1.18	<0.001
ADL score	0.96	0.91	1.02	0.161	ADL score	0.91*	0.86	0.96	<0.001
DRS score	1.14*	1.11	1.17	<0.001	DRS score	1.13*	1.10	1.16	<0.001
Age ICG	0.98*	0.98	0.99	<0.001	Age ICG	0.99*	0.98	0.99	<0.001
Behaviour	1.55*	1.36	1.78	<0.001	Behaviour	1.40*	1.26	1.57	<0.001
A probability value of <0.05 was considered significant and indicated with * next to the OR									

A logistic regression analysis showed that being unsatisfied with support from family and friends was the highest predictor for burden and high burden among the variables in Table 2 in the total population studied and in all subgroups.

Overall, ICGs who were unsatisfied with support from family and friends were more likely (OR1.85; 95%CI 1.53–2.23) to perceive burden compared to informal caregivers who were satisfied with support when all other measured confounders were held constant. The association between being unsatisfied with support and high burden was slightly stronger with an odds ratio of 1.97 (95%CI 1.67–2.33).

In the subgroup of ICG caring for a low impaired older person, the odds of perceiving burden when being unsatisfied with support was higher (OR2.54; 95%CI 1.42–4.54) than when satisfied with support. The odds ratio of perceiving high burden was 2.66 (95%CI 1.44–4.89) when being unsatisfied with support in this subgroup.

When caring for a mildly impaired older person, being unsatisfied with support from family and friends was associated with burden and high burden with odds ratios of 1.61 (95%CI 1.06–2.44) for burden and 2.55 (95%CI 1.70–3.82) for high burden.

In the group of moderately to severely impaired older people, ICG who were unsatisfied with support had a higher chance of perceiving a burden (OR1.86; 95%CI 1.48–2.33), and were also more likely to perceive a high level of burden (OR1.79; 95%CI 1.48–2.17) compared with ICG who were satisfied with the support they receive from family and friends.

Discussion

Main results

This study showed a significant positive association between feeling unsatisfied with the support provided by friends and family and perceived burden among ICG of non-institutionalised frail older people. These results were consistent for the three groups of impairment level of the frail older person.

The results confirm the hypothesis of the recent qualitative study that feeling supported in providing informal care to frail older people is associated with developing caregiver burden[10]. In that study, adult daughters of community-dwelling frail older people who reported to feel sufficiently supported by friends and family tended to have a lower level of burden than women who were unsatisfied with the support they received.

Strengths and limitations

Although the importance of social support for ICG in general is not a new finding [7, 25, 26], our results add to the evidence that perceived social support and subjective caregiver burden are associated in the context of caring for frail older people.

Strengths of this study are the large number of frail older people and ICGs included in the study. This is important when drawing recommendations for policy makers to promote early needs assessment and prevention. Another strength is that thanks to the large number of participants and the focus on the specific frail older population, a stratification in different levels of impairment was possible to analyse the association between perceived social support and subjective caregiver burden according to impairment level of the frail older person.

A significant limitation of this study was that only one ’yes/no’ item was available in the interRAI-HC on the perception of informal social support. This measure lacks sensitivity and context. ‘Feeling supported’ can be interpreted in many ways depending on the context and psychosocial status of the ICG. Future research on social support in the context of informal caregiving should define clearly the type of social support assessed and use measures and instruments that are more sensitive to personal and contextual factors of the ICG[7]. In this study we could only assess whether the ICG was satisfied or not. Qualitative research investigating why ICG are dissatisfied and what is effective social support according to the experience of the ICG could be helpful in developing social support interventions[27].

Another limitation is that ‘time spent caring’ could not be included in the final analysis. The variable had a strong correlation with ‘cohabitation’ and therefore the two could not be inserted in the model at the same time. The final selected model was the model with the best fit for all variables. A possible explanation for the large correlation between the two variables could be that many cohabiting ICG filled out that they spent 24 hours per day on caring. Time spent caring is an important factor in determining the role of the ICG, as well as distance for non-cohabiting ICG [23, 28].

Recommendations for primary care practice

Early detection of risk factors or signs of burden is important to prevent ICGs from getting overburdened, so that they will not experience negative health outcomes as a result of caring, and to help them cope with caring for their loved ones. It is often difficult for ICGs to admit to themselves (and even more difficult to others) that they are in need of social support from family and friends. The care provided by the ICG is not always visible to others [10]. It is important that primary care providers can detect this often under reported need, and that they can help the ICG in finding support in their own social network. Del Pino Casado et al (2018) recommend the promotion of increasing perceived social support by interventions to make the ICG feel more connected rather than to build new connections[7]. This might be even more necessary for spouses than for adult children since they are less likely to seek informal support [28]. Support groups are a valuable intervention to increase social support and reduce psychological effects of informal care on the ICG [9, 29, 30]. Keeping in mind the recommendation of del Pino Casado et al to focus on feeling connected instead of building connections, family group conferences are promising interventions to increase perceived social support for the informal caregiver. More research is needed on the effect of family group support interventions to increase perceived informal support for ICG caring for older people[29].

Conclusion

In this study the association between perceived social support and subjective caregiver burden was explored in the context of caring for frail older people. ICGs that were unsatisfied with support from family and friends were more likely (OR1.85; 95%CI1.53–2.23) to experience burden compared to informal caregivers that were satisfied with support. These results were consistent for the three groups of impairment level of the frail older person analysed. Although our cross-sectional study cannot infer a causal relationship, our findings underline the importance of perceived social support in relation to caregiver burden reduction. Interventions to improve perceived social support that focus on the informal caregiver to feel more connected to others are worth evaluating.

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Chapter 6

Discussion

General aim and outline of the thesis

The aim of this doctoral thesis was to explore the concept of social support for informal caregivers caring for community-dwelling frail older persons from the point of view of the primary informal caregiver. The different studies performed in the scope of this thesis added to a better understanding of how informal caregivers experience providing care for community-dwelling frail older people and how they experience social support in this role.

First, the literature was reviewed systematically to study the effectiveness of existing support services targeting informal caregivers of community-dwelling frail elderly (chapter 2). Second, a descriptive qualitative longitudinal study was conducted to get a more in-depth insight in the lived experience of adult daughters caring for their community-dwelling frail parents (chapter 3) and in the process of accepting social support (chapter 4). To test a hypothesis from this descriptive qualitative study that satisfaction with support from family and friends was related to the experienced caregiver burden, a cross-sectional quantitative study was designed using data from informal caregivers in the Protocol 3 study projects (chapter 5).

Main results

Chapter 2

This chapter reports a systematic literature review performed to answer the following research question: ***What are the known effects of different types of support services targeting informal caregivers of community-dwelling frail elderly?***

We identified different types of interventions to support informal caregivers of community-dwelling frail elderly. Some evidence was found for the effectiveness of respite care interventions, psychosocial interventions at individual caregiver level, group support and ICT support interventions. While respite care is aimed at unburdening the caregiver by temporarily taking over the care for the elderly, psychosocial and educational support interventions aim at strengthening the caregiver in his ability to better manage and cope with the caregiving role. It was clear that no single intervention could answer all relevant physical, psychological and social support needs of an informal caregiver caring for a frail elderly at home. We recommended that integrated support packages where the content of the package is tailored to the individual caregivers' physical, psychological and social needs should be preferred when supporting informal caregivers of frail elderly. It requires an intense collaboration and coordination between all parties involved.

Since the publication of this systematic review as a research paper [1] in 2012, new insights have been published that are supplementary in answer to the research question of our systematic review. We performed a new search (December 2019) in Medline with the same search strategy (limited to work after 2010) as described in chapter 2. This resulted in 154 hits, all primary studies and no systematic reviews. The reference lists of 2 relevant articles were scanned [2, 3]. The relevant articles found during this new search illustrate the evolution towards more research on integrated support as recommended in our systematic review's conclusion. Janse et al (2014) for example studied the effects of an integrated care intervention for frail elderly on informal caregivers' perceived health, objective and subjective burden and quality of life [2]. The authors conclude that integrated care models aimed at the frail elderly can also be beneficial for informal caregivers. They observed a significant reduction in subjective burden. No effects were seen on time investment, what implies that integrated care interventions as studied by Janse et al (2014) could be implemented without demanding additional time investment from the informal caregiver. Yu (2016) described the development of a health and social collaborative case management model (HSC-CM) and tested its effects on health outcomes of informal caregivers [3]. The effects of the HSC-CM were cautiously positive as they showed a significant reduction in perceived caregiver burden (p=0.030). Other rather small effects of the HSC-CM model were a better social role functioning (p=0.047), improvement in vitality (p=0.049) and a better general well-being (p=0.049). Both Janse et al (2014) and Yu (2016) confirm our conclusion that an integrated approach to providing support for informal caregivers of community-dwelling frail elderly is beneficial and more high-quality research is needed to further develop effective integrated support models and interventions for informal caregivers of community-dwelling frail elderly.

Chapter 3

Chapter 3 presented the results of a qualitative study to better understand the experiences of adult daughters caring for a community-dwelling frail older parent. The research question was: ***How do non-cohabiting adult daughters experience caring for their frail ageing parents who live in their own homes?***

We performed an in-depth analysis of the experience of eleven daughters caring for their frail older parents. Four main themes could be identified. (1) being a caregiver as a natural process in life; (2) the perception and consequences of caregiving activities; (3) sharing care and (4) finding a good balance between caring for an ageing parent and other responsibilities.

This study provided more insight in the experiences of women caring for an ageing parent. Many activities of the informal caregiver are not very visible to other family members and professionals and encompass continuous activities like protecting the parent and managing the parental household. These invisible activities may be energy consuming and considered difficult because they induce emotional distress. Women can feel burdened with a great responsibility, as they do not want to let their parents down. Supporting networks that help in both visible and invisible activities may prevent overburden. Acquiring help from formal care providers sometimes is a difficult process for the informal caregiver, as there may be pressure from the older persons to postpone this as long as possible.

Chapter 4

In this chapter we report the process of accepting social support as experienced by the women that participated in our qualitative longitudinal study. The research question in this study is: ***What elements are central in the process of accepting social support when caring for a frail older parent?*** The qualitative longitudinal design allowed to document changes over time. Although every participant's experience during the one year study period was unique, similarities in the process of accepting social support could be identified. Five elements are central in this process: initial resistance, barriers, facilitators, turning points and outcomes. To facilitate the process of accepting social support, informal caregivers should be supported in expressing their feelings, preferences and needs better and in setting boundaries.

Chapter 5

This chapter reports the results of a quantitative cross-sectional study analysing the association between informal caregiver's subjective burden and perceived social support in providing informal care to community-dwelling frail older people and the research question in this chapter was: ***What is the relationship between perceived social support and subjective burden in providing informal care to community-dwelling frail older people?***

In this study the association between perceived social support and subjective caregiver burden was explored in the context of caring for community-dwelling frail older people. This study showed a significant positive association between feeling unsatisfied with the support provided by friends and family and perceived burden among informal caregivers of non-institutionalised frail older people. Informal caregivers that were unsatisfied with support from family and friends were more likely (OR1.85; 95%CI1.53–2.23) to experience burden compared to informal caregivers that were satisfied with support. These results were consistent for the three groups of impairment level of the frail older person analysed. Although our cross-sectional study cannot infer a causal relationship, our findings underline the importance of perceived social support in relation to caregiver burden reduction. The results confirm the hypothesis of the qualitative study in chapter 3 that feeling supported in providing informal care to community-dwelling frail older people is associated with caregiver burden.

Discussion of interesting findings

Invisible care made visible

The different care activities mentioned by the women in the qualitative study could be divided into visible and invisible activities. An interesting finding in this study was the fact that the women experienced the invisible care activities (e.g. protecting, managing,…) as more difficult than the visible care activities (e.g. grocery shopping, laundry,…). This could be explained by the fact that the invisible care activities were more emotionally loaded than the visible care activities and were not easy to demarcate in time. Being the protector of the parents was experienced as very time and energy consuming for the daughters as it burdened them with a great responsibility. The women described these invisible activities as to be ‘constant on their minds’.

The fact that the invisible activities are difficult to express in terms of time spent, it poses problems when estimating the extent of the care provided and the estimated cost [4-6]. Cès et al (2016) calculated for informal caregivers of community-dwelling frail older people the monetary value of their time investment per caregiving task based on time spent and the salary of a professional who would do the same. The estimated cost of informal care ranged between 620 euros and 1189 euros per month, depending on the level of impairment of the frail older person and whether the informal caregiver and frail older person lived together or not. These are actually low estimates. The authors of the study highlight that ‘monitoring’ could not be included in the estimate. Partly because of technical reasons (risk of double counting simultaneous activities) and partly because it was impossible for the informal caregivers they interviewed to estimate how much time they spend monitoring the frail older person [4].

Support for informal caregivers, whether formal or informal, is often focused on the instrumental care activities (visible activities) while it is the invisible care activities like protecting and supervising that cause the most stress [7, 8]. The women interviewed in our qualitative study received help from family members (mainly siblings) and professional caregivers. It was striking that the help was predominantly covering the visible care activities (table 2 in chapter 3). This help from others can partly relieve the caregiver, but the biggest stressors often remain without support. The fact that important caregiving activities like protecting, monitoring, etc. often remain invisible to others can give a distorted image of the actual care burden experienced by the informal caregiver and of the unspoken and unmet need for support [9].

The difficult process of accepting support

For the informal caregivers in our qualitative study it was not obvious to accept that they needed support from others in the care for their frail older parents. An important personal barrier for accepting social support was having difficulties expressing their feelings, preferences and needs. The women who experienced this as a barrier formulated two main reasons for it to be difficult. For some it was difficult to express their feelings and thoughts because they felt chaos in their head. Some women said they didn’t know the correct words that matched their feelings and that they didn’t know how to explain how they felt to others who are not in their situation. It has to be noted that the women included in this study were all women without a migration background. It is likely to believe that not being able to express feelings would be an even larger barrier for informal caregivers from ethnic minority groups. Culture and language have an impact on expressing feelings and accepting support [10, 11].

Being able to set boundaries facilitates the process of accepting support. The women who knew what was within or beyond their own possibilities and were willing to admit that, had less difficulties accepting instrumental social support for those activities they felt not capable of. In contrast, women who preferred to keep control over all caregiving activities, even if the level of care passed beyond their own capabilities, often struggled to accept support. Informal caregivers could benefit from learning how to express their feelings, preferences and needs better and how to set boundaries [12]. Trust is an important issue in the acceptance of social support [13]. Having a good relationship of trust between the different caregivers and the care receiver is crucial [14]. Having a confidant, a person who you can turn to is an important facilitator. In most cases it was in first place a husband or a sister. An Australian study examining why informal caregivers of frail older people are not using available respite services found that concerns regarding trustworthiness and quality of support from others including both family and formal support services held the informal caregivers from accepting respite care [15].

Feeling connected rather than building connections

It was not the size of the network around the informal caregiver that was the most important, but the quality of the relationships. The women in our qualitative study who struggled the most with the caregiving activities were those who ‘felt’ alone, who experienced little support from family and friends [8]. This was confirmed in our quantitative study [16]. Informal caregivers that were unsatisfied with support from family and friends were more likely (OR1.85; 95%CI1.53–2.23) to experience burden compared to informal caregivers that were satisfied with support.

Del Pino Casado et al (2018) recommend the promotion of increasing perceived social support by interventions to make the informal caregiver feel more connected rather than to build new connections [17]. This might be even more necessary for spouses than for adult children since they are less likely to seek informal support [18]. Support groups are a valuable intervention to increase social support and reduce psychological effects of informal care on the informal caregiver [19-21]. Keeping in mind the recommendation of del Pino Casado et al to focus on feeling connected instead of building connections, family group conferences are promising interventions to increase perceived social support for the informal caregiver [22, 23].

A person-centred and goal-oriented care approach can be helpful in supporting informal caregivers. In this approach the primary focus of support interventions targeting informal caregivers is no longer the reduction of negative effects caused by providing care like burden, but the main focus will be on the individual informal caregiver's own needs and goals and on the relationship between care receiver and care provider [24, 25]. It is a positive approach, characterized by an important emphasis on individual strengths and resources and on collaboration [24, 25]. This approach can help to improve the informal caregiver's experience in his role as a caregiver and he can be encouraged to accept social support. By putting the emphasis on the collaborative relationship between informal caregiver and professional care provider when giving support, the informal caregiver will feel more connected with the professional care provider, recognized in his role as informal caregiver and involved in the care team around the community-dwelling frail older person.

Reflection on the methodology

A systematic literature review, a qualitative longitudinal study design and a quantitative cross-sectional study design were used in this thesis. This mixed method approach helped to gain a broader perspective of the research topic [26-28]. The advantage of a quantitative study with a well-designed selection process and a representative sample of the study population is that the findings can be consistent and reliable and that it can be generalized to a broader population. The advantage of a qualitative study is that it can provide more detailed information to explain a complex issue. Qualitative research allows to explore experiences of the study participants and gives them a voice. Both approaches, quantitative and qualitative, are complementary. To fully profit from the added value of a mixed method approach, results from the quantitative and qualitative component of the overall study must be integrated [28]. In this thesis the findings from the qualitative study provided a hypothesis to be tested in the quantitative study.

All research is in some form shaped by the perspective of the researcher. A researcher's background and position may impact the research from study design to reporting of the findings [29, 30]. It is important that the researcher pays attention to the influence that his own position can have on e.g. the choice of the research topic, the angle of the research, the methods chosen to provide an answer to the research question, the choice of themes and language used in the interpretation of data, the choice of main findings to be reported [29]. It is therefore important that the researcher reflects on his own role and position in all phases of the research [30]. In qualitative research this process of continual internal dialogue and critical self-evaluation of the researcher's own position and the acknowledgement that this position can influence the research is called 'reflexivity' [29]. Reflecting on my own background and position, I am a woman in my thirties, trained as a nurse, working as a nurse lecturer and researcher and among other roles a mother, daughter, sister. Regarding the choice for the subject of informal caregivers in this thesis, I have no personal experience as an informal caregiver. The informal caregivers I know or knew personally in my own network are: my mother being an informal caregiver for her brother with a minor mental disability, my neighbour being an informal caregiver for her frail older partner and my late grandparents who were informal caregivers of my late aunt with early onset dementia.

The **systematic literature review** at the start of the study allowed us to get acquainted with the concept of support for informal caregivers and to study the effectiveness of existing support services targeting informal caregivers of community-dwelling frail elderly. To increase the quality of our literature review we used the Prisma Checklist for transparent reporting of systematic reviews and meta-analyses [31]. The fact that we focused on studies with quantitative data is perhaps a weakness. In addition to evidence of effectiveness, evidence of feasibility, appropriateness and meaningfulness found in qualitative studies could have told us a lot about how an intervention is related to the context in which it is given and how the intervention is experienced by the population.

This lack of qualitative information from the literature review confirmed us in our idea to design a **qualitative longitudinal study** to get a more in-depth insight in the lived experience of informal caregivers caring for community-dwelling frail parents. Although this qualitative longitudinal method is time consuming, the benefits were well worth achieving [31, 32]. Eleven informal caregivers participated in the first wave of this study and nine women completed the entire year of follow-up interviews. This may seem few to researchers not acquainted with this method, but because of the multiple contacts over the course of one year it resulted in a large amount of chronological in-depth interview data. We deliberately chose to only include women who were the primary carer for their community-dwelling frail older parents. This population was chosen because, besides spouses, it is also an important group at risk for adverse outcomes caused by providing care [33]. To determine if the parent was frail, we used the same inclusion measures as in the Protocol 3 study (the Edmonton Frail Scale, an adapted version of the Katz scale or a dementia diagnosis) [34]. Because of the exploratory in-depth approach, this method provided us an insight into the experience of these women caring for their frail older parents. The regular follow-up interviews allowed us to see an evolution in the participant's experience and particularly in their process of accepting social support [35]. The advantage of conducting monthly short telephone interviews was that small changes were still fresh in the participant's memory [36]. Another advantage was that the regular contact facilitated the relationship between participants and research team. It should be noted however that despite the advantages, the monthly phone calls and interviews could have had a therapeutic effect on the informal caregiver [36]. Telling their story and reflecting on the care they provide and the support they receive could have had an accelerating effect on their process of accepting social support. In retrospect, seen the multidimensional character of frailty [37], more emphasis could have been put on analysing differences in the experiences of the women based on the individual elder's frailty profile.

The analysis of the first wave of interviews in the qualitative study resulted among other results in a hypothesis that satisfaction with support from family and friends was associated with caregiver burden. To test this hypothesis, we designed a **quantitative cross-sectional study** that allowed us to analyse the association between informal caregiver's subjective burden and perceived social support in providing informal care to community-dwelling frail older people. Strengths of this study are the large number of informal caregivers and frail older people included in the study. The large number of participants also made it possible to analyse the association between perceived social support and subjective caregiver burden for 3 different impairment levels of the frail older person. A significant limitation of this study was that only one 'yes/no' item was available in the interRAI-HC on the perception of informal social support. This measure lacks sensitivity and context. 'Feeling supported' can be interpreted in many ways depending on the context and psychosocial status of the informal caregiver. Future research on social support in the context of informal caregiving should define clearly the type of social support assessed and use measures and instruments that are more sensitive to personal and contextual factors of the informal caregiver [17]. In this study we could only assess whether the informal caregiver was satisfied or not. Qualitative research investigating why informal caregivers are dissatisfied and what is effective social support according to the experience of the informal caregiver could be helpful in developing social support interventions [38]. Another limitation in this quantitative cross-sectional study was the fact that only the gender of the frail older person was recorded in the interRAI-HC, not the gender of the informal caregiver. Because of that it wasn't possible to run an additional analysis limited to only female daughters (cfr. the qualitative study).

Recommendations for further research

- Concerning the design of future studies to evaluate the effectiveness of caregiver support interventions, mixed methods including economic evaluations and qualitative methods should be considered.
- At present, few studies did incorporate long-term effect evaluation. Future research should focus on the effect of social support for informal caregivers over a longer period of time.
- In future research that aims at improving social support and also understanding the dynamics of social support for informal caregivers, we recommend research methods that include the active participation of informal caregivers as co-researchers and experts. Participatory action research should be considered [39].
- More research is needed on methods to improve communication and decision-making between family members like Family Group Conferencing. Family Group Conferencing was developed for and within child welfare [22]. Some researchers in the field of elderly care are examining the potential of this method to enhance the resilience and relational autonomy of older persons [23]. In a similar way the potential to use this method to enhance the social support within the direct network of informal caregivers could be tested.

Implications for practice

- We learned that it is often difficult for informal caregivers to admit that they are in need of social support, especially when it concerns support with the invisible care activities [8]. It is important that primary care providers can also detect this often under reported need for support with the invisible care activities, like monitoring and protecting, and not only offer support that unburdens them from visible household activities and actively explore this at several stages.
- Screening tools to map the support needs of informal caregivers may be helpful, if they also target the invisible care activities [40].
- Since talking about these invisible care activities and support needs related to them is not easy for many informal caregivers, professional care providers need communication skills to be able to have an in-depth conversation about the informal caregiver’s actual support needs, to help the informal caregiver to express their feelings and in setting boundaries.
- A person-centred and goal-oriented care approach can be helpful in supporting informal caregivers. It is a positive approach, based on the informal caregiver’s strengths and possibilities.
- Professional care providers should invest in building trusting relationships with the informal caregivers. In a trusting relationship, informal caregivers will be less restrained to share their own support needs concerning the more emotionally difficult invisible care activities. This will facilitate their process of accepting social support.
- Professional care providers and confidants within the close network of the informal caregiver have an important role in helping the informal caregiver to become aware of the seriousness of the situation leading to turning points in process of accepting support.

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Samenvatting

Summary

Samenvatting

Bij het ouder worden verkiest een grote meerderheid van de mensen om zo lang mogelijk thuis te worden verzorgd door zijn mantelzorgers in plaats van naar een woonzorgcentrum te verhuizen.

In de zorgsector is er tevens een verschuiving van residentiële zorg naar thuiszorg merkbaar waarin ook de mantelzorger een meer prominente rol krijgt.

Hoewel veel mantelzorgers voldoening vinden in de zorg voor een familielid of vriend, kan het met momenten zwaar zijn en kan de mantelzorger fysieke en mentale gezondheidsproblemen, financiële problemen en sociaal isolement ervaren door het verlenen van mantelzorg.

Overheden en zorginstanties erkennen de toenemende rol van de mantelzorger in de zorg voor thuiswonende kwetsbare ouderen en zijn zich bewust van de noodzaak om hen te ondersteunen in hun rol en zo een kwaliteitsvolle thuiszorg voor kwetsbare ouderen te garanderen.

In Vlaanderen krijgt mantelzorg en mantelzorgondersteuning de laatste jaren meer aandacht door onder andere initiatieven als het Vlaams mantelzorgplan 2016-2020 van voormalig minister van Welzijn, Volksgezondheid en Gezin, Jo Vandeurzen [1] en door grootschalige onderzoeksprojecten naar mantelzorg en mantelzorgondersteuning in België en Europa [2-4].

Er zijn verschillende ondersteunende maatregelen en diensten voor mantelzorgers beschikbaar zoals onder andere mantelzorgpremie, flexibele verlofstelsels, respijtzorg, psychosociale ondersteuning. Maar desondanks is onderbenutting van beschikbare ondersteunende maatregelen en diensten een blijvend probleem bij mantelzorgers van thuiswonende kwetsbare ouderen.

Sociale ondersteuning door mensen die dicht bij de mantelzorger staan en dus laagdrempeliger zijn, worden mogelijks beter aanvaard. Internationale studies naar sociale ondersteuning aan mantelzorgers tonen positieve resultaten op psychologische uitkomsten zoals ervaren zorgbelasting.

Om te kunnen begrijpen hoe mantelzorgers de mantelzorg ervaren en hoe ze sociale ondersteuning ervaren, is onderzoek nodig dat het concept van mantelzorgondersteuning onderzoekt vanuit het oogpunt van de mantelzorger zelf.

De verschillende studies gebundeld in dit proefschrift hebben als doel om kennis te verwerven over hoe mantelzorgers van thuiswonende kwetsbare ouderen de mantelzorg ervaren en hoe zij sociale ondersteuning in deze rol ervaren.

Als eerste deelstudie, beschreven in **hoofdstuk 2**, is een systematisch literatuuronderzoek gedaan met volgende onderzoeksvraag: **Wat zijn de bekende effecten van verschillende soorten ondersteunende diensten gericht op mantelzorgers van kwetsbare ouderen in de gemeenschap?**

Verschillende soorten interventies zijn geïdentificeerd geweest om mantelzorgers van thuiswonende kwetsbare ouderen te ondersteunen. Er is enig bewijs gevonden voor de effectiviteit van respijtzorg, individuele psychosociale ondersteuning, groepsondersteuning en ICT-ondersteuning.

Terwijl respijtzorg gericht is op het ontlasten van de zorgverlener door tijdelijk de zorg voor ouderen over te nemen, zijn de psychosociale ondersteuningsinterventies gericht op het versterken van de zorgverlener in zijn vermogen om de rol van mantelzorger beter aan te kunnen.

Geen enkele interventie op zich kan tegelijkertijd voldoen aan alle fysieke, psychologische en sociale ondersteuningsbehoeften van een mantelzorger die voor een kwetsbare thuiswonende oudere zorgt. Ondersteuning op maat die is afgestemd op de fysieke, psychologische en sociale behoeften van de individuele mantelzorger verdient de voorkeur bij het ondersteunen van mantelzorgers van kwetsbare ouderen.

In **hoofdstuk 3 en 4** staan de resultaten neergeschreven van een kwalitatief longitudinaal onderzoek met vrouwen die als volwassen dochter de primaire mantelzorger zijn van hun kwetsbare thuiswonende ouders.

In **hoofdstuk 3** is dieper ingegaan op de ervaring van de vrouwen met het verlenen van mantelzorg aan hun ouders. De onderzoeksvraag in dit deelonderzoek is: **Hoe ervaren niet-samenwonende volwassen dochters de zorg voor hun kwetsbare thuiswonende ouder wordende ouders?**

We hebben de ervaringen van elf volwassen dochters die voor hun kwetsbare thuiswonende ouder wordende ouders zorgen, bevraagd en geanalyseerd. Vier hoofdthema's zijn geïdentificeerd. (1) Zorgverlener zijn als een natuurlijk proces in het leven; (2) De perceptie en gevolgen van mantelzorgactiviteiten; (3) Zorg delen en (4) Een goed evenwicht vinden tussen de zorg voor een ouder wordende ouder en andere verantwoordelijkheden.

Veel activiteiten van de mantelzorger zijn niet zichtbaar voor andere familieleden en professionals en omvatten continue activiteiten zoals het beschermen van de ouder, toezicht houden en het beheren van de agenda van de ouders. Deze onzichtbare activiteiten worden als moeilijk ervaren omdat ze emotionele stress veroorzaken en energieslopend zijn. Ondersteuning door mensen in het sociale netwerk van de mantelzorger die kunnen helpen bij zowel zichtbare als onzichtbare activiteiten kan overbelasting voorkomen. Hulp vragen aan formele zorgverleners is soms een moeilijk proces voor de mantelzorger.

Hoofdstuk 4 beschrijft het proces van acceptatie van sociale ondersteuning zoals ervaren door de vrouwen in onze kwalitatieve longitudinale studie. De onderzoeksvraag in deze studie is: **Welke elementen staan centraal in het proces van acceptatie van sociale ondersteuning bij de zorg voor een kwetsbare oudere ouder?**

Het kwalitatieve longitudinale onderzoeksdesign heeft het mogelijk gemaakt om veranderingen in de tijd te documenteren. Hoewel de ervaring van elke deelnemer tijdens de studieperiode van één jaar uniek was, konden overeenkomsten in het proces van acceptatie van sociale ondersteuning worden geïdentificeerd. Vijf elementen staan centraal in dit proces: (1) aanvankelijke weerstand; (2) barrières; (3) facilitators; (4) keerpunten en (5) effecten op de mantelzorger.

Om het proces van acceptatie van sociale ondersteuning te vergemakkelijken, moeten mantelzorgers worden ondersteund om hun gevoelens, voorkeuren en behoeften beter te uiten en grenzen voor zichzelf te stellen.

Hoofdstuk 5 rapporteert de resultaten van een kwantitatief cross-sectioneel onderzoek met meer dan 6000 mantelzorgers van kwetsbare thuiswonende ouderen. De onderzoeksvraag in dit hoofdstuk was: **Wat is de relatie tussen de ervaren sociale ondersteuning en de subjectieve mantelzorgbelasting bij het verlenen van mantelzorg aan kwetsbare thuiswonende ouderen?**

Deze studie toont een significant positief verband aan tussen een gevoel van ontevredenheid over de steun van familie en vrienden en de waargenomen zorgbelasting bij mantelzorgers van kwetsbare thuiswonende ouderen.

Mantelzorgers die niet tevreden zijn met de steun van familie en vrienden, hebben meer kans (OR1.85; 95% CI1.53-2.23) om overbelasting te ervaren in vergelijking met mantelzorgers die tevreden zijn met de sociale ondersteuning. Deze resultaten zijn consistent voor de drie groepen, ingedeeld volgens de mate van beperking van de kwetsbare ouderen.

Hoewel ons cross-sectioneel onderzoek geen causaal verband kan aantonen, onderstrepen onze bevindingen wel het belang van de ervaren sociale ondersteuning in relatie tot het verminderen van mantelzorgbelasting.

Tot slot, het onderzoek gedaan in het kader van dit proefschrift leert ons onder andere dat het voor mantelzorgers vaak moeilijk is om toe te geven dat ze sociale ondersteuning nodig hebben, vooral als het gaat om ondersteuning bij onzichtbare zorgactiviteiten zoals beschermen en toezicht. Het is belangrijk dat eerstelijnszorgverleners hier aandacht voor hebben en deze vaak onuitgesproken nood aan sociale ondersteuning kunnen detecteren en bespreekbaar kunnen maken.

Referenties

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Summary

A vast majority of people, when aging, choose to be taken care of at home by their informal caregivers as long as possible instead of moving into a nursing home.

In the health care sector we also notice a shift from residential care towards home care, in which also the informal caregiver is being given a more prominent part.

Although many informal caregivers find satisfaction in taking care of a family member or friend, this can prove to be quite heavy at times, so that the informal caregiver may even experience physical and mental health problems, financial problems and social isolation just by providing informal care.

Governments and healthcare authorities acknowledge the increasing role of the informal caregiver in the care for community-dwelling frail elderly, and they are aware of the necessity to support them in their role so as to guarantee a qualitative home care for the frail elderly.

In Flanders informal care and support for informal caregivers have been paid more attention to during the last few years by, among others, initiatives like the Flemish informal care plan 2016-2020 of the former minister of welfare, public health and family, mister Jo Vandeurzen [1] and by large-scale research projects on informal care and informal care support in Belgium and Europe [2-4].

Several supporting measures and services for informal caregivers are available, such as among others informal care fees, flexible leave systems, respite care and psycho-social support. But nevertheless under-utilization of the available supporting measures and services is a lingering problem with informal caregivers of the community-dwelling frail elderly.

Social support by people close to the informal caregiver, and hence more accessible, is possibly better accepted. International studies on social support for informal caregivers show positive results on psychological effects such as experienced burden.

In order to be able to understand how informal caregivers experience informal care and social support, it is necessary to do some research into the concept of informal care support starting from the point of view of the informal caregiver himself.

The various studies bundled in this doctoral thesis aim to gain knowledge on how informal caregivers of community-dwelling frail elderly experience the informal care and how they experience social support in this role.

The first part of the study, **described in chapter 2,** is a systematic literature review on the following research question: **What are the known effects of different types of support services targeting informal caregivers of community-dwelling frail elderly?**

Several kinds of interventions have been identified in order to support informal caregivers of community-dwelling frail elderly. Some evidence has been found for the effectiveness of respite care, individual psychosocial support, group support and ICT support.

While respite care aims at unburdening the caregiver by temporarily taking over the care for the elderly, the interventions of psychosocial support aim at reinforcing the caregiver's ability to cope with the role of informal caregiver.

No intervention whatsoever can at the same time meet all the needs for physical, psychological, and social support of an informal caregiver taking care of a frail elderly living at home. Customized support adapted to the physical, psychological and social needs of the individual caregiver is preferred when supporting caregivers of the frail elderly.

Chapters 3 and 4 show the results of a qualitative longitudinal study on women who, as the adult daughter, are the primary caregiver of their community-dwelling frail parent(s).

In **chapter 3** we dig deeper into the experience of the women when giving informal care to their parents. The research question in this part of the research is: **How do non-cohabiting adult daughters experience caring for their frail ageing parents who live in their own homes?**

We have studied and analyzed the experiences of eleven adult daughters taking care of their frail aging parents still living at home. Four main themes have been identified. (1) Being a caregiver as a natural process in life; (2) The perception and the consequences of informal caregiving activities; (3) Sharing care and (4) Finding a good balance between the care for an aging parent and other responsibilities.

Many activities of the caregiver are not visible for other members of the family and professionals, and include continuous activities such as protecting the parent, supervision and agenda management of the parents. These invisible activities are seen as difficult because they cause emotional stress and are energy consuming. Support by people within the social network of the caregiver, who can help with visible as well as invisible activities, can prevent overpressure. To ask for help to formal caregivers is sometimes a difficult process for the informal caregiver.

Chapter 4 describes the process of accepting social support in the way it is experienced by the women in our qualitative longitudinal study. The research question in this study is: **What elements are central in the process of accepting social support when caring for a frail older parent?**

The design of the qualitative longitudinal study has enabled us to document changes in time.

Although the experience of every participant was unique during the study period of one year, similarities in the process of acceptance of social support could be identified. Five elements are central in this process: initial resistance, barriers, facilitators, turning points and results.

In order to facilitate the process of social support informal caregivers should be supported to better express their feelings, preferences and needs and to define limits for themselves.

Chapter 5 reports the results of a quantitative cross-sectional study of more than 6000 informal caregivers of community-dwelling frail elderly. The research question in this chapter was: **What is the relationship between perceived social support and subjective burden in providing informal care to community-dwelling frail older people?**

This study shows a significant positive link between a feeling of dissatisfaction with the support of family and friends and the perceived care burden that informal caregivers of frail elderly living at home have.

Informal caregivers who are not satisfied with the support of family and friends, are more likely (OR1.85; 95% CI1.53-2.23) to experience burden compared with informal caregivers who are satisfied with the social support. These results are consistent for the three groups, classified according to the degree of impairment of the frail elderly.

Although our cross-sectional study cannot demonstrate any causal relation our findings do emphasize the importance of the experienced social support in relation to the decrease of informal care burden.

Finally, the research in the context of this doctoral thesis shows us, among others, that it is often difficult for informal caregivers to admit that they need social support, especially when it concerns support with the invisible care activities such as protection and supervision. It is important for primary care providers to pay attention to this and to be able to detect and make negotiable this often unspoken need for social support.

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Dankwoord

Dankwoord

In dit hoofdstuk neem ik jullie even mee naar hoe het doctoraatsverhaal begon. Zelfs voor het begon.

In 2007 koos ik ervoor een nieuwe weg in te slaan, die van het levenslang leren. Dat pad leidde me naar de masteropleiding verpleeg- en vroedkunde aan de UA waar ik een nieuwe wereld leerde kennen. Die van het wetenschappelijk onderzoek. Het was Prof Monique Elseviers die als één van de eersten mijn interesse en talent voor het wetenschappelijk onderzoek zag en me stimuleerde om in die richting verder te gaan. Monique, dankjewel om me de wereld van het wetenschappelijk onderzoek te leren kennen. Er werd toen een zaadje geplant dat uiteindelijk geleid heeft tot onder andere dit doctoraat.

In juni 2009, tijdens mijn laatste examenperiode in de master V&V, kreeg ik plots een telefoontje van Bart Geurden, toen nog mijn docent. Hij vroeg of ik geïnteresseerd was om onmiddellijk na afstuderen mee te werken aan het kortdurend onderzoeksproject over de begeleiding van voedingsteams. Ik had toen ook net gesolliciteerd aan Karel de Grote Hogeschool voor een functie als docent verpleegkunde. Maar het zaadje dat geplant was tijdens de masteropleiding was aan het kiemen en ik kon deze kans niet laten liggen. Bart, dankjewel om me toen die kans te geven om me verder te verdiepen in het wetenschappelijk onderzoek. Bedankt voor de fijne samenwerking als collega aan UA en aan KdG.

Net op het juiste moment kwam er op de afdeling Eerstelijns- en Interdisciplinaire Zorg (ELIZA) aan UA een vacature als onderzoeksmedewerker in het consortium dat de zorgvernieuwingsprojecten Protocol 3 zou evalueren. Dit was mijn kans om me verder te ontplooien als onderzoeker. Tijdens de Protocol 3 periode, die uiteindelijk 7 jaar heeft geduurd, heb ik veel geleerd. Over onderzoek, over samenwerking, over mezelf. Het was een heel leerrijke periode. Ik wil dan ook al mijn collega's bedanken die doorheen de jaren mee aan dat project gewerkt hebben. Thérèse, Johanna, Sophie, Sam, Patrick, Olivier, Caroline, Anne-Sophie, Jean, Anja, Christiane en alle anderen die soms voor korte of iets langere tijd deel uitmaakten van ons Protocol 3 team: bedankt voor de fijne samenwerking!

Het is tijdens de Protocol 3 studie dat ook mijn interesse voor mantelzorg nog meer groeide. Ik startte, puur uit interesse, in 2012 met een systematic review over interventies gericht op mantelzorgers (hoofdstuk 2 in dit proefschrift). "Fantastisch, waarom maak je er niet ineens een doctoraatstraject van?" zei Roy Remmen.

Ondertussen zijn we 8 jaar later en leg ik de laatste hand aan mijn doctoraatsproefschrift. Het is dan toch gelukt. Mijn doorzettingsvermogen is op de proef gesteld geweest. Docent op KdG, onderzoeker op UA, daarnaast nog doctoreren en sinds 2016 ook mama. Tijdens mijn doctoraatstraject zijn er verschillende uitdagingen op mijn pad gekomen, maar gelukkig kon ik steeds blijven rekenen op de steun van een heel aantal personen. Ik wil graag even de tijd nemen om hen hiervoor te bedanken.

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Annelies, na de verhuis naar GKC kwam ik enkel nog op maandagen naar Wilrijk. In deze eindfase van mijn doctoraat vond ik ook steun bij jou. Mijn bureaugenoot en lotgenoot. Ja, ook jij kan dit: volhouden! En dat geldt trouwens voor iedereen van het pre-doc clubje. Ik wens jullie veel cake, en veel steun van mekaar. Een verdediging, dat is trakteren op een grote cake waarschijnlijk?

Elisa en Joanna, bedankt voor jullie bijdrage in de datacollectie en analyse van het kwalitatief onderzoek.

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Naast het Protocol 3 onderzoek op UA, werkte ik de afgelopen jaren ook als docent verpleegkunde aan de Karel de Grote Hogeschool. Ik wil ook mijn leidinggevenden en collega's op KdG bedanken. Door hun steun maakten ze het mij mee mogelijk om mijn onderwijsopdracht op KdG te combineren met de onderzoeksopdracht op UA en mijn doctoraat. Van bij de start van mijn carrière aan KdG kon ik op de steun rekenen van mijn opleidingshoofd Ann Cleerbout. Nina Geuens en de collega's van het expertisecentrum Zorgstroom dank ik ook uitdrukkelijk voor de fijne steun en aanmoedigingen.

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Mama, ik kan niet anders dan met jou beginnen. Je bent er altijd voor mij. Hoeveel keer heb je me niet gevraagd hoe je kon helpen? Iets nalezen, vertalen, op Helena letten, eten brengen,… . Ja, het heeft allemaal enorm geholpen. Gewoon er zijn was soms al genoeg. Bedankt mama, ik hou van je.

Papa, je doctoreerde zelf op UIA in 1977 als dokter in de wiskunde. Als kind dacht ik dat je een dokter was die cijfers genas. Bedankt om mijn voorbeeld te zijn. Een intelligent man waar ik naar opkijk. Bedankt om me te steunen en om in me te geloven, zelfs vanaf de andere kant van de aardbol. Hopelijk zien we mekaar snel weer.

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Curriculum vitae

CURRICULUM VITAE

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Publicaties

Eerste auteur

2019 **Lopez Hartmann**, M., De Almeida Mello, J., Anthierens, S., Declercq, A., Van Durme, T., Cès, S., Verhoeven, V., Wens, J., Macq, J., & Remmen, R. (2019). Caring for a frail older person: the association between informal caregiver burden and being unsatisfied with support from family and friends. *Age and ageing*, *48*(5), 658-664.

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Co-auteur

2018 Lambert, A. S., Declercq, A., Flusin, D., Bastiaens, H., de Almeida Mello, J., **Lopez Hartmann**, M., ... & Van Durme, T. (2018). Protocol 3-Geïntegreerd samenvattend rapport.

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Appendix

Hoe ervaren dochters de mantelzorg voor hun bejaarde ouder? Een kwalitatief onderzoek

Publicatie in Huisarts Nu

Lopez Hartmann, M., van Assche, E., Welvaert, J., Anthierens, S., Verhoeven, V., Wens, J., & Remmen, R. (2017). Hoe ervaren dochters de mantelzorg voor hun bejaarde ouder?. *Huisarts Nu*, *46*(3), 130-135.

Hoe ervaren dochters de mantelzorg voor hun bejaarde ouder?

Een kwalitatief onderzoek

Auteurs

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- **Elisa Van Assche** en **Joanna Welvaert** waren studenten geneeskunde ten tijde van dit onderzoek en zijn nu beiden huisarts.
- **Sibyl Anthierens, Veronique Verhoeven, Johan Wens** en **Roy Remmen** zijn verbonden aan het Centrum Huisartsgeneeskunde, vakgroep Eliza, Universiteit Antwerpen.

Inleiding

Gezondheidsprofessionals benadrukken vaak de belangrijke rol die informele mantelzorgers opnemen om de kwetsbare oudere zolang mogelijk thuis te houden.[1]

De zorg voor een kwetsbare hulpbehoevende oudere kan echter een grote uitdaging betekenen, die bij de mantelzorger kan leiden tot lichamelijke en psychologische problemen, een financiële draaglast en sociaal isolement.[2,3]

De meeste mantelzorgers zijn vrouwen, doorgaans dochters, schoondochters en echtgenotes.[4] In de zorg voor ouderen kan het zijn dat volwassen kind-mantelzorgers meer stressoren ervaren dan partner-mantelzorgers.[5]

Vanwege hun leeftijd, meestal tussen 30 en 65 jaar, maken dochter-mantelzorgers vaak ook belangrijke levensgebeurtenissen mee: ze huwen, krijgen kinderen of kleinkinderen, zijn professioneel actief en zorgen tegelijkertijd voor een bejaarde ouder. Niet-inwonende dochters maken minder gebruik van bestaande diensten, in vergelijking met inwonende dochters, echtgenotes en andere familieleden.[6]

Vraagstelling

Tot nu toe zijn er weinig studies die aandacht besteden aan de echte ervaringen van mensen die de zorg voor een geliefd familielid opnemen.

Dochters zijn een belangrijke hoeksteen in het verlenen van deze mantelzorg. Daarom is het cruciaal dat er wordt rekening gehouden met hun unieke ervaringen en noden. Dit leidde tot het idee om via een kwalitatief onderzoek een beter inzicht te krijgen in de ervaringen van volwassen dochters die de zorg voor een bejaarde ouder op zich nemen.

De centrale onderzoeksvraag hierbij is: *'Hoe ervaren niet-inwonende volwassen dochters de zorg voor hun thuiswonende hulpbehoevende bejaarde ouder(s)?'*

Methode

Om een beter inzicht te krijgen in de dagelijkse ervaringen van niet-inwonende volwassen dochters in de zorg voor een bejaarde ouder, werd gebruikgemaakt van een fenomenologische onderzoeksopzet. Dit soort onderzoek beschrijft wat mensen met elkaar gemeen hebben, wanneer ze geconfronteerd worden met hetzelfde fenomeen.[7] In deze studie was dat de zorg voor een kwetsbare hulpbehoevende bejaarde ouder.

Om in deze studie geïncludeerd te worden, moest de informele mantelzorger een volwassen dochter zijn van een thuiswonende kwetsbare oudere, niet-inwonend bij de ouder zijn, woonachtig in het grootstedelijk gebied Antwerpen en Nederlands als moedertaal hebben.

De ethische commissie van het Universitair Ziekenhuis van Antwerpen keurde deze studie goed. Deelnemers gaven hun geïnformeerde toestemming voor deelname. Alle gegevens werden verwerkt met respect voor de privacy van de deelnemers.

De interviews liepen van maart tot augustus 2012 en duurden een à twee uur. Alle interviews vonden plaats bij de deelnemers thuis in afwezigheid van de ouder(s), zodat ze zich vrijer konden uitdrukken.

Interviews werden op een geluidsdrager opgenomen en woord voor woord getranscribeerd. NVIVO-softwareversie 10 werd gebruikt om alle transcripts te bewaren en om de gegevensanalyse te vergemakkelijken.

Twee onderzoekers lazen en synthetiseerden de transcripts onafhankelijk van elkaar. Tekstfragmenten werden gecodeerd. Na vergelijking tussen de onderzoekers werden de codes hernoemd en gegroepeerd tot een lijst met hoofdthema's: mantelzorger zijn als natuurlijk proces in het leven; perceptie en gevolgen van mantelzorgeractiviteiten; het delen van zorg en het vinden van een goede balans tussen de zorg voor een bejaarde ouder en andere verantwoordelijkheden.

Resultaten

Algemene kenmerken

Elf vrouwen tussen 40 en 70 jaar namen deel aan deze studie. Vier vrouwen waren met pensioen, vijf vrouwen werkten en twee werkten om medische redenen niet. Van de elf vrouwen waren er acht gehuwd, twee gescheiden en één alleenstaand. Alle vrouwen, behalve één, hadden kinderen en acht van hen ook kleinkinderen.
Vier vrouwen zorgden voor beide ouders, vijf vrouwen alleen voor de moeder en twee vrouwen alleen voor de vader.

Mantelzorg, een natuurlijk proces

De redenen waarom de vrouwen in deze studie de primaire mantelzorg voor hun ouders op zich namen, waren uiteenlopend en hielden verband met hun individuele situatie. De belangrijkste waren enige dochter zijn (met of zonder broers), het oudste kind zijn of de dochter zijn die het dichtst bij de ouders woont.
De dochters vonden het hun plicht om voor hun ouders te zorgen. Het kaderde binnen het wederkerigheidsprincipe: de ouders hebben voor hun kinderen gezorgd toen ze klein waren en later, wanneer de ouders hulpbehoevend worden, is het aan de kinderen om voor hen te zorgen.
De vrouwen zegden de levenswaarden van hun ouders het beste te kennen en ze wilden er zeker van zijn dat deze waarden ook in de zorg werden weerspiegeld.
De meeste vrouwen startten hun informele mantelzorgerschap na een acute gebeurtenis, meestal het overlijden van een van de ouders of na een verblijf van een ouder in het ziekenhuis. In andere gevallen was er geen duidelijk startpunt en begon de mantelzorg bij achteruitgang van de mobiliteit of de capaciteiten van de ouders. Het is een progressief proces; dochters worden geen mantelzorger van de ene dag op de andere.
Gemeenschappelijk aan alle mantelzorgers in deze studie was dat eens ze begonnen waren met dingen te doen, zoals de was, boodschappen of het schoonmaken van het ouderlijk huis, ze dat verder bleven doen, ook al was de acute situatie voorbij. Het maakte op de duur deel uit van hun dagelijks leven.

'Toen mijn vader overleed, verbleef mijn moeder bij ons overdag op maandag, dinsdag en vrijdag... Dat gezelschap was zeer aangenaam, zowel voor mijn moeder als voor de kinderen en voor mezelf. Later bleef ze komen op dinsdag. Op een bepaald moment vroeg ik haar om haar kleurwas mee te brengen... Toen ze minder mobiel werd, ging mijn man haar 's morgens halen en 's avonds terugbrengen. Het groeide, stap voor stap. Ik heb het nooit beseft, maar nu ik erover nadenk, denk ik dat we veel voor haar doen en dat is een goede zaak.'

Wat is gekend?

- De meeste mantelzorgers zijn vrouwen, doorgaans dochters, schoondochters en echtgenotes.
- Mantelzorg kan leiden tot lichamelijke en psychologische problemen, een financiële draaglast en sociaal isolement bij de mantelzorger.
- Niet-inwonende dochters maken minder gebruik van bestaande diensten in vergelijking met inwonende dochters, echtgenotes en andere familieleden.

Wat is nieuw?

- De onzichtbare zorgtaken, zoals het beschermen van de ouder, worden beschouwd als energieverslindend en moeilijk, omwille van de emotionele aspecten.
- De vrouwen die het het moeilijkst hebben en een grotere belasting ervaren, zijn degenen die het minst steun krijgen van hun familie.
- Het inschakelen van hulp van formele zorgverleners is een soms moeilijk proces voor de mantelzorger, dat vaak zolang mogelijk wordt uitgesteld.

'Het begon toen mijn vader minder mobiel werd en het moeilijker kreeg om zijn boodschappen via de trap naar zijn appartement te dragen. Voor de zware inkopen ging ik met hem een keer per maand naar de supermarkt en hielp die dan mee naar boven te dragen. Daarna zorgde ik ervoor dat er altijd genoeg maaltijden in de diepvriezer lagen... Later merkte ik dat hij zijn medicatie niet goed nam en begon ik die voor hem per dag klaar te leggen in een medicatiedoosje en te controleren of hij ze wel had genomen. Van het een kwam het ander en geleidelijk aan begon ik meer voor hem te doen.'

Zichtbare mantelzorgactiviteiten

Tabel 1 geeft een overzicht weer van de taken die vrouwen opnemen voor hun ouders.
De manier waarop zij zichtbare en onzichtbare zorg percipiëren, was anders. De vrouwen beschouwden taken als schoonmaken, de was en de boodschappen doen niet als moeilijk of onaangenaam. De meeste van deze activiteiten waren huishoudelijke taken die ze gewoon waren te doen in hun eigen huishouden. De taak zelf en het resultaat ervan waren zichtbaar: een schoon huis, propere kleren en een

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gevulde koelkast. Hun ouders met deze dingen helpen werd gezien als een verlenging van de eigen dagelijkse routines.

‘Als ik klaar ben met schoonmaken en tegen mijn moeder zeg dat ik naar huis ga, dan lacht ze en weet ik dat ze gelukkig is.’

Het helpen van de ouders met hun persoonlijke hygiëne was een zichtbare activiteit, die in vergelijking met andere taken verschillende gevoelens opwekte. Dat werd als lastiger beschouwd, omdat het gepaard ging met lichamelijke intimiteit. De ouders naakt zien en helpen bij het nemen van een bad of bij een toiletbezoek werd niet als normaal beschouwd in een ouder-kindrelatie. De vrouwen hadden het moeilijk met het opnemen van deze taak.

‘Ik ben bereid om alles voor hen te doen, maar hen helpen bij het nemen van een bad, vooral mijn vader, daar voel ik me niet comfortabel bij.... Ik denk niet dat ik in staat ben om dat te doen, zowel op emotioneel als op praktisch vlak. Mijn moeder misschien, maar niet mijn vader.’

‘In het begin was het voor haar moeilijk om bij het douchen de hulp van een vreemde (verpleegkundige) te aanvaarden, maar nu is dat geen probleem meer. Het is lastiger wanneer ik haar help, wat af en toe gebeurt. Dan is ze krampachtig en voelt ze zich ongemakkelijk. Voor mij is het ook erg ongemakkelijk om mijn moeder zo te ervaren.’

Onzichtbare mantelzorgactiviteiten

In tegenstelling tot de zichtbare zorg viel het resultaat van onzichtbare mantelzorgtaken niet altijd op voor andere familieleden en zorgprofessionals. Onzichtbare zorg werd als stressvoller ervaren omdat die alle zorg omvat die betrekking heeft op het welzijn van de ouders en er veel emotionele aspecten bij komen kijken.
Het optreden als ‘beschermer’ of ‘manager’ nam erg veel tijd en energie in beslag omdat ze het gevoel hadden met een grote verantwoordelijkheid opgezadeld te worden.
Ze wilden hun ouders niet in de steek laten.
De vrouwen rapporteerden volgende onzichtbare activiteiten: agendabeheer van de ouders, het geven van advies aan de ouder, het beschermen van de ouder, tussenpersoon zijn, het stimuleren van zelfzorg en van sociale contacten.

Organiseren van huishouden en agenda

Naast het runnen van hun eigen huishouden, beheerden de vrouwen ook het huishouden en de agenda van hun ouders.
Het plannen, coördineren, het maken van afspraken, de opvolging van doktersbezoeken, het zoeken naar informatie over thuiszorgdiensten en over de voordelen ervan, het geven van informatie en advies en vaak ook het overtuigen van de ouders om deze diensten in te schakelen, werden als zeer tijdrovend en stressvol ervaren.

‘Ik moet aan een heleboel dingen denken, over hoe ik de zorg die ze nodig hebben ga organiseren. Kan ik het zelf doen of moet ik een professional inschakelen? Of het nu gaat om het organiseren van het vervoer naar het ziekenhuis of bellen naar de kinesitherapeut om te horen hoe de revalidatie verloopt...’

‘Ze kregen een brief van de eigenaar van het appartementsgebouw waar ze wonen met betrekking tot kosten voor de gemeenschappelijke delen van het gebouw. Dan vragen ze me om de brief te lezen, uit te leggen waarover het gaat en om mijn mening hierover te geven.’

In bescherming nemen

De vrouwen beschouwden het in bescherming nemen van de ouder ten aanzien van bepaalde emotionele confrontaties als zeer moeilijk, maar tegelijk ook zeer belangrijk.
Zo probeerden ze de ouder te beschermen door verontrustend nieuws te verbergen of door diens mentale en fysieke achteruitgang te minimaliseren.
Sommige vrouwen schakelden geen extra hulp in van professionals om hun ouder ervoor te behoeden dat ze steeds afhankelijker zouden worden van professionele zorgverleners.

‘Voor ze een poetsvrouw hadden, bracht ik in mijn handtas poetsdoeken mee en maakte ik, zonder dat ze het wisten, de wc-bril schoon toen ik op bezoek kwam, omdat ik merkte dat ze niet zo dikwijls meer poetsten.’

‘Sinds een paar weken zegt mijn moeder dat ze veel vergeet. Dan vertel ik haar dat ik ook veel vergeet. Ik lach het een beetje weg. Aan de andere kant ben ik blij dat ze naar de geheugenklas gaat in het plaatselijke dienstencentrum.’

Overtuigen van professionele hulp

De vrouwen vonden het moeilijk om hun ouders ervan te overtuigen dat ze niet meer voor zichzelf konden zorgen en dat ze professionele ondersteuning nodig hadden.
In alles wat ze deden, wilden ze de wensen van hun ouders zoveel mogelijk respecteren. Vaak verzetten de ouders zich in eerste instantie tegen hulp van vreemden. Het overtuigen van de ouder om professionele hulp te aanvaarden bleek voor de dochters erg tijdrovend en moeilijk.

‘Ik was soms beschaamd als ik in hun huis kwam. Maar hen vertellen dat het huis niet proper was, vond ik erg moeilijk. Ik wilde hun gevoelens niet kwetsen. Na enige tijd aandringen hebben ze nu een poetshulp. Ze wilden eerst geen vreemde in huis, maar anderzijds waren ze niet meer in staat om zelf het huis schoon te houden.’

Stimuleren van zelfzorg en sociale contacten

De dochters stimuleerden hun ouders vaak om actief te blijven, naar buiten te gaan en sociale contacten te onderhouden. Ook dat was een manier om de ouder te beschermen tegen immobiliteit en eenzaamheid.

‘Ze gaat nog steeds zelf naar de kruidenier of de bakker. Niet omwille van de boodschappen, maar om mensen te

ontmoeten. Ze is een heel sociaal persoon en als ze een dag geen bekend gezicht ziet, is ze droevig. Dus wij (broers en zussen) vinden het onze verantwoordelijkheid om haar een bezoekje te brengen of om haar te bellen. Het is als een stille overeenkomst tussen ons: als we weten dat een van ons bij haar op bezoek is geweest, dan voelen we ons gerust en hoeven we er niet langs te gaan.'

Delen van de zorg

Professionele hulp

De vrouwen in deze studie deelden allen minstens enkele zorgtaken met andere familieleden en professionele zorgverleners. Uit *tabel 1* blijkt in welke mate de dochter (D) taken deelde met anderen, namelijk familieleden (F) en professionals (P).

De vrouwen hadden de intentie om de zorg voor hun ouders zo lang mogelijk zelf op te nemen. Indien nodig, zouden ze in eerste instantie hulp vragen aan familie.

Het inschakelen van professionele zorgverleners was voor hen meestal een laatste optie.

Vertrouwen hebben in professionele zorgverleners bij de zorg voor hun ouders werd vaak als stressvol ervaren omdat ze er zeker van wilden zijn dat hun ouders respectvol en waardig werden behandeld. Daarom bleef de primaire mantelzorger, zelfs na het delegeren van een deel van de zorg aan een professional, de centrale figuur die de zorg verder coördineerde. Zij was degene die uiteindelijk het best wist wat er gaande was in het leven van de ouders en de communicatie opnam met alle andere spelers, familieleden en professionals.

'Je weet dat er verschillende soorten professionele zorg bestaan, maar in feite blijf je het inschakelen van externe hulp uitstellen, omdat je je ouders niet wilt belasten met het aanvaarden van hulp van een vreemde. En dan komt het tot een punt dat de situatie ontspoort. Het is moeilijk om te beslissen wanneer professionele hulp onvermijdelijk wordt.'

Hulp van broers en zussen

Hulp van een broer of zus werd beschouwd als het gemakkelijkst om te aanvaarden. De zorg gedeeld met zussen bestond voornamelijk uit huishoudelijke taken.

Broers hadden, in vergelijking met zussen, eerder de neiging om zich te ontfermen over duidelijk omschreven taken, zoals financiën, klusjes of dragen van zware boodschappen. De dochters waren van oordeel dat broers de zorg voor een ouder op een andere manier percipiëren dan zussen.

'Een zoon is anders dan een dochter. Mijn broers komen elke week bij onze ouders op bezoek. Maar de was doen, boodschappen doen, koken, dat is voor mijn zus en voor mij.'

Hulp van anderen

De vrouwen in dit onderzoek vermeldden ook hun eigen echtgenoot als comantelzorger. De echtgenoot werd vaak gevraagd om te helpen met het vervoer of klusjes.

Ze deden ook vaak een beroep op andere familieleden

Tabel 1: Zichtbare en onzichtbare mantelzorgactiviteiten.

Zichtbare activiteiten	**D1**	**D2**	**D3**	**D4**	**D5**	**D6**	**D7**	**D8**	**D9**	**D10**	**D11**
Berichten/rekeningen	D		D		F			F	F	F	
Inkopen	D	F	D	F		D	D	P	F	P	
Helpen met eten						D		P			
Koken	D	F		P			F	P	F	P	
Schoonmaken	F	P	P	P	P	D	P	P	F	P	D
Intieme hygiëne			P	P	P	P	P	P	P	P	P
Overzicht medicatie			D	P	P	D	P	P	F	D	
Klusjes	F	F		F	F	D	F	F	F	F	F
Tuinieren						D		F			
Vervoer	D	F		P	F	D	D	P	F	P	F
Wassen en strijken	D	F	F	D		D	D	D	F	P	D
Onzichtbare acitiveiten	**D1**	**D2**	**D3**	**D4**	**D5**	**D6**	**D7**	**D8**	**D9**	**D10**	**D11**
Advies aan de ouder geven	D	D	D	D	D	D	D	D	F	D	D
Agendabeheer	D	D	D	D	D	D	D	D	F	D	D
In bescherming nemen	D	D	D	D	D	D	D	D	F	D	D
Tussenpersoon	D	D	D	D	D	D	D	D	F	D	D
Zelfzorg stimuleren	D	F	D	D	D		D	D	F	F	D
Sociaal contact stimuleren	F	D		D	D		D	D	F	F	D

Lege ruimte: geen informele zorg
D: activiteit door de dochter;
F: dochter krijgt hulp van andere familieleden;
P: dochter krijgt hulp van professionele zorgverleners.

➜

voor specifieke taken, zoals verplegen of haartooi, afhankelijk van het beroep van het familielid.

Delen van taken

Zichtbare taken werden vaker met anderen gedeeld dan onzichtbare taken. Zichtbare taken waren beter omschreven en vooral minder emotioneel beladen dan onzichtbare taken, zoals het beschermen van de ouders. De communicatie over bepaalde gevoelige zorgthema's, zoals persoonlijke hygiëne, werd wel bemoeilijkt om de normale dochter-ouderrelatie te willen beschermen.

Vrouwen die zich echt gesteund wisten door hun familie, delegeerden meer taken aan familieleden en professionals en voelden zich ook minder belast. Vrouwen die geen of weinig steun van anderen ondervonden, hadden meer problemen om de zorg aan anderen over te laten en voelden ook een grotere belasting.

Hoe dochters de belasting ervaren in combinatie met de zelfgerapporteerde mate van ondersteuning door andere familieleden, is vermeld in *tabel 2*.

'Ik voel me niet alleen. Ik weet dat als ik zeg dat ik me niet goed voel, anderen de zorg voor mijn moeder zullen overnemen.'

'De volledige last werd op mijn schouders gelegd. Eén broer woont ver weg en de vrouw van mijn andere broer was ziek. Ik ben het altijd die voor onze vader moet zorgen en op een bepaald moment kon ik dat niet meer aan. Dat is de reden waarom ik wilde dat hij zich liet opschrijven op de wachtlijst van een woonzorgcentrum.'

Balans tussen mantelzorg en eigen gezin

De mantelzorg werd ervaren als een constant proces van zoeken naar een evenwicht tussen de zorg voor een bejaarde ouder en andere verantwoordelijkheden.

De vrouwen balanceerden tussen de eigen huishoudelijke taken en het gezin (echtgenoot, kinderen en kleinkinderen) en die van de ouder. Sommige vrouwen integreerden de zorg voor hun ouders in de dagelijkse planning.

'Iedere ochtend ga ik naar mijn vader, samen met mijn man, om te zien of alles in orde is... Om 12 uur gaan we terug naar huis omdat mijn man altijd werkt van 14 tot 22 uur. Dan pas kan ik beginnen met mijn eigen huishouden. Eigenlijk verkies is om 's morgens bij het opstaan eerst mijn eigen taken te doen, maar dat is nu niet mogelijk.'

Sommige vrouwen maakten een duidelijk onderscheid tussen oudertijd en tijd voor het gezin, anderen wilden liever meer tijd spenderen met andere familieleden of vrienden, maar handelden er niet naar. Vaak was er sprake van een onderliggend schuldgevoel.

'Ik zou op vakantie willen gaan met mijn man, maar iets houdt me tegen. Ik weet dat mijn kinderen het niet erg vinden om de zorg voor mijn vader over te nemen, maar gaan ze dat doen op dezelfde manier als ik? Nee, ze zullen hem eerder bellen om te vragen of alles in orde is in plaats van er elke dag langs te gaan.'

Bespreking

Belasting van de mantelzorger

Deze studie is een diepgaande analyse van de ervaringen van elf dochters die de zorg voor hun kwetsbare bejaarde ouders opnemen. Mantelzorg bleek een continu proces dat was ingebed in de dagelijkse routine van de dochters. De zorg voor hun bejaarde ouder(s) werd ervaren als een normaal onderdeel van hun leven, als een daad van wederkerigheid.

De onzichtbare taken, in het bijzonder het beschermen van de ouder, werden als moeilijker ervaren dan de zichtbare taken, omdat er veel emotionele aspecten bij komen kijken. De dochters vonden het beschermen van de ouder zeer tijdrovend en energieverslindend omdat het hen opzadelt met een grote verantwoordelijkheid.

Sommige zichtbare taken werden met anderen gedeeld.

De vrouwen die het meest met mantelzorgtaken worstelden, waren degenen die het gevoel hadden er alleen voor te staan. Een goede vertrouwensrelatie tussen de verschillende mantelzorgers en de zorgontvanger is van cruciaal belang.[8]

Uit onze resultaten blijkt dat de mantelzorgers vaak beheertaken op zich nemen die ze met hun familie en formele zorgverleners, zoals verpleegkundigen, moeten bespreken. De dochters ervoeren professionele zorg als een laatste optie.

Vrouwen vonden het zeer belangrijk om naast de ouder ook tijd door te brengen met anderen, maar handelden er vaak niet naar. Dikwijls lag hiervoor een onderliggend schuldgevoel ten aanzien van de ouder aan de basis.

Ondersteuning van de mantelzorger

Gezondheidswerkers in de eerste lijn zijn, omwille van de opgebouwde vertrouwensrelatie, goed geplaatst om de noden van mantelzorgers te identificeren en de mantelzorgers te ondersteunen.[9] Helaas hebben deze professionals vaak een beperkte kennis van het complete spectrum van de noden van de mantelzorger, inclusief de sociale en emotionele implicaties van het mantelzorger zijn.[10]

Tabel 2: Ervaren belasting en ondersteuning door familieleden.

	D1	D2	D3	D4	D5	D6	D7	D8	D9	D10	D11
Ervaren belasting door de dochter	Hoog	Gemiddeld	Hoog	Gemiddeld	Laag	Hoog	Gemiddeld	Hoog	Geen belasting	Gemiddeld	Gemiddeld
Ervaren ondersteuning door de familie	Nooit	Altijd	Soms	Altijd	Altijd	Nooit	Altijd	Soms	Altijd	Altijd	Soms

Het is belangrijk dat professionals in de gezondheidszorg snel kunnen detecteren wat de daadwerkelijke ondersteuningsnoden zijn. In plaats van de algemene vraag: *'Hoe gaat het met je?'* te stellen, zal de professional een nauwkeuriger antwoord krijgen op de vraag *'Hoe ga je om met de zorg voor je ouders?'* Een eenvoudig en snel instrument dat de noden van de mantelzorger detecteert, kan eerstelijnszorgverleners helpen om de mantelzorger beter te ondersteunen.

Betrekken van de mantelzorger

De vrouwen in deze studie vonden het hun verantwoordelijkheid om de wensen van hun ouders te respecteren en ervoor te zorgen dat anderen, met name de professionele zorgverleners, dat ook deden. Daarom dient men bij het opstellen van een zorgplan meer rekening te houden met cliëntgestuurde zorg en met de inbreng van de mantelzorger in het besluitvormingsproces.
Eerstelijnsprofessionals zouden, mits akkoord van de patiënt, mantelzorgers systematisch moeten uitnodigen op vergaderingen van het multidisciplinair zorgteam. Dit zorgt ervoor dat de mantelzorger zich meer gerespecteerd voelt als expert in de dagelijkse zorgnoden van de patiënt en dat de coördinatie van de zorg thuis kan verbeteren.

Beperkingen van het onderzoek

Dit onderzoek kent enkele beperkingen. Zo werden alleen vrouwen geïncludeerd die een dochter-ouderrelatie hadden met de persoon voor wie ze de zorg opnamen. We kozen deze doelgroep omdat de meeste informele mantelzorgers vrouwen zijn die voor hun ouders zorgen.[4]
Hoewel goedgekeurd door de ethische commissie, kende de werving van mantelzorgers via een derde partij beperkingen. Patiënten die in aanmerking kwamen voor de studie, werden door de huisarts geïnformeerd. Hij vroeg hun toestemming om te worden gecontacteerd door een onderzoeker. Deze werkwijze kan hebben geleid tot een zekere druk om aan de studie deel te nemen. Tijdens het eerste telefoongesprek met de kandidaat-deelnemers gaf de onderzoeker nochtans meer informatie over de studie en benadrukte dat er geen verplichting was tot deelname en dat niet deelnemen geen invloed zou hebben op hun arts-patiëntrelatie.
Aanvullend onderzoek is nodig naar informele mantelzorg bij migranten en minderhedengroepen, waarbij misschien andere copingstrategieën worden ingezet, aangezien migranten niet zo vaak gebruikmaken van formele zorg.[11]

Besluit

Veel mantelzorgtaken zijn niet goed zichtbaar voor andere familieleden en professionals en lopen constant door, zoals het beschermen van de ouder en het beheer van het huishouden. Deze onzichtbare taken kunnen energieverslindend zijn en worden als lastig ervaren, omdat ze aanleiding kunnen geven tot emotionele ontreddering.
Omdat zij hun ouders niet in de steek willen laten, hebben de mantelzorgers het gevoel dat ze opgezadeld worden met een grote verantwoordelijkheid. Een netwerk van familie die inspringt bij zowel zichtbare als onzichtbare taken, kan overbelasting voorkomen. Het inschakelen van hulp van formele zorgverleners is een soms moeilijk proces voor de mantelzorger, omdat die vaak, onder druk van de oudere, dit zo lang mogelijk probeert uit te stellen. ←

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