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Poster P20

“Getting the Balance Right”: Co-creating a Sensory-Integrated Balance Programme for People Living with Charcot-Marie-Tooth Disease

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Introduction:

People with Charcot-Marie-Tooth disease (CMT) experience progressive distal weakness and sensory loss, contributing to impaired postural control and increased fall risk. Balance interventions incorporating sensory integration targeting visual, vestibular, and somatosensory systems are effective in other neurological conditions, and early studies suggest potential benefit in CMT. Co-design methods can enhance the relevance, acceptability, and uptake of such interventions by incorporating lived experience.

Methods:

A series of co-creation workshops were conducted with six adults living with CMT, facilitated by physiotherapists, an expert patient, and an artist-designer. Experience-based co-design approaches were used to identify priorities for balance training, shape the content and presentation of both paper-based and digital resources, and develop strategies for engagement and dissemination within the global CMT community.

Results:

Participants emphasised the importance of individualisation, variety, and psychological safety in balance training. Their input informed the structure and delivery of a modular resource that accommodates varying abilities and preferences, while encouraging exploration of different sensory inputs.

Conclusion:

The co-designed resource offers a novel, user-informed approach to sensory-integrated balance training in CMT. While it is intended for immediate community use, insights from the co-design process will inform the refinement and evaluation of future clinical interventions and research in this area.