

Social participation in dementia

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IMPACT PARAGRAPH

This thesis aimed to gain a better understanding of the experience of social participation in dementia and the potential role of technology therein. This impact paragraph reflects on the scientific and societal impact of this thesis' main findings.

Main findings

Regarding the social participation experiences of people with dementia, the findings of this thesis reveal that participants were not overly concerned during social participation outside the home. Nonetheless, they were highly aware of the challenges and risks they faced and adapted their behaviour accordingly. Delving deeper into these adaptation processes, our findings indicate that people with dementia actively chose environments that supported continued social participation. Although spouses played a significant role in facilitating higher levels of independence in social participation, they struggled to balance their social participation needs with those of their loved ones.

In terms of the potential role of technology in promoting social participation in dementia, our findings highlight inconsistencies in the operationalisation of social participation in intervention trials, as well as the limited evidence on technology's effectiveness for people with dementia. In addition, they emphasise the significance of tailoring technology to the individual and evolving needs of people with dementia and their informal caregivers. Occupational therapists could play an important role in this tailoring process given their unique skills in advising, assessing, and instructing individuals with dementia in technology use.

Scientific and societal impact

This thesis adds to the growing body of literature on social participation from a capability-based and occupational perspective. It addresses the existing research gap concerning the potential value of technology in promoting social participation and offers directions for future research, such as the exploration of individualised methods for measuring social participation that capture individual experiences, while also allowing for cross-study comparisons. This thesis also shares practical recommendations for stakeholders involved in the development and evaluation of technological interventions in the field of social participation and dementia. These recommendations underscore the importance of tailoring technology to the evolving needs and preferences of individuals with dementia. Therefore, it is essential to integrate the development of personalised technology into clinical practice and educational curricula for future healthcare professionals, including occupational therapists.

Furthermore, this thesis offers significant implications for policymakers and those involved in the design of dementia-friendly communities. It highlights the importance of designing specialized healthcare services tailored to the needs of people with dementia living in the community and their informal caregivers. In addition, it advocates for the creation of dementia-friendly communities that respect the individuality of people with dementia, fostering a sense of social identity, comfort and safety, and promoting meaningful social participation. Within these communities, it is recommended to adapt existing environments that are familiar to an individual with dementia rather than creating separate environments for people with dementia exclusively. This approach could fulfil the wish of people with dementia to live longer in the community and, thereby, their enhance quality of life. Additionally, it may reduce caregiver burden and help mitigate the potential rise in long-term healthcare costs.

Dissemination activities

Our findings were disseminated to the scientific community through presentations at various international conferences, including the Gerontological Society of America 2021 Annual Scientific Meeting, the Occupational Science Europe Conference 2021, the World Federation of Occupational Therapists International Congress 2022, the 32nd and 33rd Alzheimer Europe conference, the World Occupational Science Conference 2022, and the Global Conference of Alzheimer's Disease International 2022. Furthermore, our findings were made widely accessible to researchers through open-access publications in international journals.

Additionally, our findings were communicated with other relevant stakeholders. The DISTINCT project's Best Practice Guidance, aimed at improving technology development and implementation in dementia care, included recommendations based on our findings. This guidance is intended to reach people with dementia, their caregivers, policy makers, technology developers, and researchers. We also shared our findings through presentations to healthcare professionals working in dementia care, people living with dementia and their loved ones, for instance at different Alzheimer Cafés in the Netherlands and at Uniklinikum Aachen (Germany). Moreover, we actively used social media platforms to disseminate findings and participated in the Researcher UK podcast.

Taken together, our dissemination strategies facilitated the advancement of knowledge regarding social participation experiences in dementia, fostering collaboration among a wide range of stakeholders, including people with dementia, caregivers, researchers, healthcare professionals, policy makers, and technology developers across the globe.