

# Social participation in dementia

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## SUMMARY

Social participation is a relevant determinant of successful ageing and living well with dementia. It is associated with various benefits, such as improved health, life satisfaction, and a strengthened sense of autonomy and identity. However, people with dementia frequently experience a decline in social participation and express unmet social needs, highlighting the urgent need for interventions addressing social participation. Due to the rapid technological developments in recent years, the use of technology has gained significant attention in promoting social participation. Although it holds potential, the existing body of literature is scarce. Therefore, this thesis aims to gain a better understanding of the experience of social participation in dementia and to explore the potential role that technology can play therein. It is divided into two parts. Part I explored experiences of social participation in dementia, while Part II focused on the potential added value that technology can bring in promoting this participation.

### Part I: Experiences of social participation in dementia

**Chapter 2** revolves around the experiences of people with dementia living in the community regarding their out-of-home social participation. It employed a mixed methods approach to explore participants' concerns and considerations. While participants were not particularly concerned during the engagement in social activities outside the home, they were highly aware of the challenges and risks they faced. To handle these challenges, participants needed to be more alert and attentive to certain aspects, such as finding the way, not falling, and keeping track of valuables. The findings highlight how people with dementia living in the community draw on their capabilities to successfully adapt to challenges in their social participation.

**Chapter 3** delved deeper into these adaptation processes using dyadic interviews with people with dementia living in the community and their spouses. A key finding was that participants with dementia actively chose environments that supported the continuation of social participation, such as familiar places or people who made them feel understood and human. Spouses perceived the changing world of social participation as a balancing act, balancing their current and past roles while additionally balancing their own social participation needs with those of their loved ones.

### Part II: Technologies and social participation in dementia

To explore the potential added value of technology in promoting social participation among older adults with and without dementia, a systematic review was conducted (**Chapter 4**). A key finding was the inconsistency observed in the approaches taken by

included studies in operationalising social participation. This lack of consistency impacted the comparability of study findings. Furthermore, the review's findings unscored the limited body of evidence in this field, with only three studies identified that specifically focused on people with dementia. While these findings did indicate that technological interventions held promise in alleviating loneliness and enhancing social support in cognitively healthy older adults, no conclusions could be drawn regarding their effectiveness in people with dementia.

In **Chapter 5**, the feasibility and acceptability of a Geographic Information System (GIS) based mobile application ('Viamigo') was evaluated among people with dementia and their spouses. A major finding of this feasibility trial was the need for technology to be tailored to the individual and unique needs of individuals with dementia and their respective informal caregivers. The chapter highlights the importance of involving people with dementia in the development process of technology to better tailor technology to their needs and preferences.

Taking into account the importance of catering social participation technology to individual needs, **Chapter 6** discussed the potential role occupational therapists can play therein. It highlights the unique skills of occupational therapists in advising the tailoring and personalisation of technology to address the occupational needs of individuals with dementia. Moreover, it reflects on the skills of occupational therapists in the ongoing assessment and training of technology use within daily life. The chapter sets out recommendations for practice, highlighting the need for collaboration between all relevant stakeholders involved in the development and implementation process, such as occupational therapists, researchers, technology developers, and people with dementia.

In **Chapter 7**, the main findings are discussed, together with methodological considerations and implications for practice and future research.