

Social participation in dementia

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Social participation in dementia:
Experiences and the role of technology
through an occupational lens

Pascale Heins

Colophon

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Social participation in dementia
Experiences and the role of technology through
an occupational lens

Dissertation

To obtain the degree of Doctor at Maastricht University,
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CHAPTER 1

General Introduction

DEMENTIA AND SOCIAL HEALTH

The proportion of older adults in the world population is steadily growing. By 2030, 1 in 6 individuals across the globe are expected to be aged 60 years or older.¹ Along with a growing life expectancy, the prevalence of dementia is projected to increase. Dementia is a clinical syndrome characterized by a cognitive decline that impacts an individual's functioning in daily life.² It affects more than 55 million people worldwide and is one of the leading causes of dependency and disability among older adults.³ By 2050, an estimated 152 million people will be living with dementia worldwide.⁴ Accordingly, the costs of long-term healthcare in European countries are rising.⁵

In their dementia plans, national policies draw on the concept of *ageing in place*,⁶ expecting older adults to live at home for as long as possible, including people living with dementia.⁷ This matches the needs and wishes of people living with dementia who generally favour remaining in their own homes for as long as possible.^{8,9} A growing body of literature focuses on living well with dementia.¹⁰ In a recent study regarding the understanding of living well among people with dementia, 1339 individuals cited having positive relationships with others as a key element.¹¹ Conversely, having company is one of the most common unmet needs reported by people with dementia living in the community.^{12,13} Addressing the social needs of people living with dementia is, therefore, crucial.

In the past decade, there has been a shift in focus in the context of social health in dementia, moving away from an impairment-led approach towards a more capability-led approach. This capability-led approach focuses on how people living with dementia adapt to changes dementia brings to their lives, without neglecting potential negative experiences and losses.¹⁴⁻¹⁶ It originates from the new formulation of health by Huber et al.¹⁷, defining health as the ability to adapt and self-manage. This new and dynamic formulation moves away from the static WHO definition of health, defining health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity".^{18(p.1)} Besides physical and mental health, Huber et al.¹⁷ introduce a new conceptualisation of social health, including its three dimensions: (1) the capacity to fulfil one's potential and obligations, (2) the ability to manage life with some degree of independence, and (3) the ability to participate in social activities.^{15,17} This thesis predominantly focuses on the latter dimension, the dimension of social participation.

Social participation in dementia

The INTERDEM taskforce on Social health in dementia operationalised the new formulation of social health for people with dementia. According to this operationalisation, social participation is seen as "the act of being occupied or involved in meaningful activities and

social interactions and having social ties and relationships, which are meaningful to the person living with dementia".^{15(p.9)} Participation in meaningful social activities is a relevant determinant of successful ageing^{19,20} and living well with dementia.^{11, 21} In people with dementia, social participation has been found to be associated with improved health, life satisfaction and quality of life.²²⁻²⁴ It also promotes a sense of autonomy and identity.^{25,26} Moreover, a higher level of social participation is associated with a lower dementia risk.²⁷ However, previous studies show that people with dementia living in the community can experience a decline in social participation.²⁸⁻³⁰ Therefore, a growing body of literature endorses the urgent need for interventions targeting social participation in people living with dementia.

The development and evaluation of social participation interventions are limited by a lack of clarity and homogeneity of the concept of social participation. Various studies evaluating social participation have been using different concepts with similar definitions, such as social connectedness or social engagement.^{31,32} Hence, there is a need to gain a better understanding of the concept of social participation in dementia. Few studies investigated how people with dementia perceive their social participation, including facilitators and barriers leading to changes in social participation.^{15,28} Moreover, too little attention has been paid to how people with dementia living in the community seek a balance between limitations and opportunities and, thereby, adapt to these changes.^{16,17} This knowledge is essential for developing and evaluating psychosocial interventions for people with dementia living in the community that foster social participation.

While a variety of definitions and terms have been used to describe social participation, this thesis will use the recently updated definition of social participation by Levasseur et al.³³ who refer to social participation as "a person's involvement in activities providing interactions with others in community life and in important shared spaces, evolving according to available time and resources, and based on the societal context and what individuals want and is meaningful to them".^(p.8)

An occupational perspective

As previously stated, people with dementia consider participation in meaningful occupations as essential to living well with dementia.¹¹ An occupation can be defined as a "specific individual's personally constructed, nonrepeatable experience".^{34(p.139)} The term 'occupation' is often used interchangeably with the term 'activity'. However, the two terms hold distinct meanings. An occupation, on the one hand, is a personally constructed experience that is bound to a unique physical, temporal, and sociocultural environment. An activity, on the other hand, is a culturally shared idea of a category of action.³⁴ To illustrate, we all have a general idea of what the activity 'going to a restaurant' entails, such as entering a restaurant, ordering food, eating the food, and potentially socializing

with others. However, when considering 'going to a restaurant' as an occupation, it additionally involves the subjective experience and unique context associated with it. While going to a restaurant might be enjoyable for one person with dementia, it might be a stressful experience for another person (e.g., due to difficulties to follow a conversation in a noisy restaurant). Moreover, even when visiting the same restaurant different times, each visit can have unique aspects that influence the experience.

The Person-Environment-Occupation Model of occupational performance³⁵ is widely used in occupational therapy practice and research to explore the dynamic and transactional relationships between a person, an environment and an occupation. Each person has individual and changing needs, abilities and qualities. According to the model, a person performs occupations in an environment that can both facilitate or hinder the performance. The environment encompasses not only the physical aspects of an environment but also social, cultural, institutional and socio-economic aspects. Hence, there is a continuous interaction between the person and the environment which shapes occupational performance. In other words, the dynamic experience of a person living with dementia to engage in meaningful occupations within an environment can be seen as occupational performance. The model highlights that this experience cannot be separated from its context.

The chapters of this thesis are informed by an occupational perspective on social participation in dementia. In the context of social participation and dementia, an occupational perspective recognizes the multifaceted concept that is not only influenced by changes on an individual level but also by contextual factors and interactions with the environment.³⁶ In other words, the chapters of this thesis acknowledge that occupations can't be separated from the context in which they are situated.³⁷

TECHNOLOGY AND SOCIAL PARTICIPATION IN DEMENTIA

With the rapid technological developments of recent years, the use of technology in fostering older adults' social participation has gained significant attention. Several systematic reviews highlighted the potential added value of technological interventions in alleviating social isolation among older adults, as well as promoting social support and social connectedness.^{38,39} However, literature on technologies in the field of social participation and dementia was, at the beginning of this project, scarce. Technology was mostly used to provide support in performing daily activities, such as providing reminders and instructions for daily activities and promoting safe outdoor mobility.⁴¹ However, little was known about the use of technology to meet the social and occupational needs of people living with dementia.^{40,41}

Only one systematic review could be identified that explored the effects of technology on the social participation of people living with dementia.⁴² The findings of the review suggest that technology could promote social participation in people living with dementia. However, with a rapidly evolving technological landscape, it is important to keep abreast with research including new technological developments. This indicates a need to further explore the potential role of technology in promoting the social participation of people with dementia living in the community. This need is further reinforced by the global action plan of the World Health Organization that has been established to improve the lives of those living with dementia and their families, as well as reduce its impact on communities and countries. The action plan encourages member states to foster the development and evaluation of technological interventions that match not only the physical and psychological needs but also the social needs of people living with dementia.⁴³

THESIS AIM AND OUTLINE

This thesis aims to gain a better understanding of the experience of social participation in dementia and the role that technology can play therein. To gain a comprehensive understanding of this experience, this thesis combines a synthesis of existing literature with both qualitative and quantitative research methods. The use of research methods and interpretation of findings was informed by an occupational perspective.

This thesis has been divided into two parts. Part I revolves around the question *What are the experiences of social participation in dementia, and what factors shape these experiences?* Part II aims to answer the question: *What is the potential added value of technologies in improving the social participation of people living with dementia?*

Part I: Experiences of social participation in dementia

The first part of this thesis aims to answer the following research questions:

1. *What are the concerns and considerations of people with dementia regarding their social participation?*

Chapter 2 uses a mixed methods approach to gain an understanding of what people living with dementia consider and are concerned about when participating in social activities outside the home.

2. *How do people with dementia experience their social participation?*

Chapter 3 explores the lived experiences of social participation among people with dementia and their spouses using a qualitative study employing dyadic interviews.

Part II: Technologies and social participation in dementia

The second part of this thesis centres around the following research questions:

1. *What are the effects of technologies on social participation in older adults with and without dementia?*

Chapter 4 systematically reviews the literature on the effects of technological interventions that have been studied to improve social participation among older adults with and without dementia.

2. *How feasible is the use of the GIS-based intervention 'Viamigo' in people with dementia and their informal caregivers?*

Chapter 5 uses a mixed methods approach to evaluate the feasibility of a mobile application for out-of-home social participation in people living with dementia and their loved ones.

3. *What role could occupational therapists play in the design and implementation of technologies that promote social health in dementia?*

Chapter 6 discusses the potential role of occupational therapists in the intersection of technology and social health in dementia.

General discussion

Chapter 7 discusses the main findings of the research reported in the present thesis. It encompasses methodological limitations, as well as implications for clinical practice and potential future directions for research.

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Part 1

Experiences of social participation
in dementia



CHAPTER 2

People with dementia being out and about: A mixed methods study on out-of-home social participation

Pascale Heins, Camilla Malinowsky, Lizzy M.M. Boots, Marjolein E. de Vugt,
& Anna Brorsson

Submitted



CHAPTER 3

**Social participation outside the home,
a changing world: A qualitative interview
study on the experiences of people with
dementia and their informal caregivers**

Pascale Heins, Gianna Kohl, An Neven, Frans R.J. Verhey, Marjolein E. de Vugt,
& Lizzy Boots

Submitted

Part 2

Social participation and technology
in dementia





CHAPTER 4

The effects of technological interventions on social participation of community-dwelling older adults with and without dementia: A systematic review

Pascale Heins, Lizzy M.M. Boots, Wei Qi Koh, An Neven, Frans R.J. Verhey,
& Marjolein E. de Vugt

Journal of Clinical Medicine, 2021

ABSTRACT

Social isolation in community-dwelling older adults with dementia is a growing health issue that can negatively affect health and well-being. To date, little attention has been paid to the role of technology in improving their social participation. This systematic review aims to provide a systematic overview of the effects of technological interventions that target social participation in community-dwelling older adults with and without dementia. The scientific databases Medline (PubMed), PsycINFO, CINAHL, Web of Science, and the Cochrane Library were systematically searched and independently screened by two reviewers. Results were synthesized narratively. The methodological quality of included studies was independently assessed by two reviewers. In total, 36 studies of varying methodological quality were identified. Most studies evaluated social networking technology and ICT training programs. Three studies focused on people with dementia. Quantitative findings showed limited effects on loneliness, social isolation, and social support. Nevertheless, several benefits related to social participation were reported qualitatively. Social interaction, face-to-face contact, and intergenerational engagement were suggested to be successful elements of technological interventions in improving the social participation of community-dwelling older adults. Rigorous studies with larger sample sizes are highly needed to evaluate the long-term effects of technology on the multidimensional concept of social participation.

INTRODUCTION

The world's population is ageing due to demographic changes. In 2020, 727 million people were aged 65 and over. According to the Department of Economic and Social Affairs of the United Nations, 1.5 billion people worldwide will be above this age by 2050.¹ At the same time, the prevalence of dementia and other age-related neurodegenerative conditions is steadily increasing. Currently, there are 50 million people living with dementia worldwide. This number is expected to increase to 152 million by 2050.²

Social isolation is a growing health issue in the aged population.^{3,4} It has been reported that more than 75 million adults in Europe experience social isolation.⁵ In the United States, 24% of community-dwelling older adults were estimated to be socially isolated.⁶ Recently, these numbers have increased rapidly across the globe due to the COVID-19 pandemic, especially among people with cognitive impairment.⁷ In a recent Dutch study, more than half of the community-dwelling participants with cognitive decline reported not having any face-to-face contact with friends (52%) or family (57%) during the pandemic.⁷ This kind of social isolation can negatively affect their mental and physical health,^{8,9} mortality,¹⁰ well-being, and quality of life.¹¹ Furthermore, poor social engagement is positively associated with an increased dementia risk.¹²⁻¹⁴ Correspondingly, social relationships and participation in social activities can have a protective effect against cognitive decline and dementia.^{14,15} However, community-dwelling people with dementia tend to experience difficulties participating in social situations, which might be the result of limited emotion perception,¹⁶ irritability, and fluctuating mood.¹⁷ Moreover, due to the progressive deterioration of cognitive skills and the stigma associated with dementia, they are more likely to avoid social situations out of embarrassment or to even lose their interest in socializing in the community.^{18,19} In combination with difficulties in spatial orienting, this avoiding behaviour can result in limited participation in social activities, which subsequently can lead to social isolation and feelings of loneliness.^{19,20} While social isolation refers to the objective lack of social connections, loneliness refers to the subjective feeling of lacking social connections.²¹

There is a growing body of literature that has endorsed the urgent need for interventions targeting social participation in older adults. The definition of social participation, however, varies in the literature. In the renewed definition of health by Huber et al., social participation is one of the domains of social health and is described as "the ability to participate in social activities including work".^{22(p.2)} Whereas this definition focuses on the ability to socially participate, the definition by Levasseur et al. focuses on the element of social interaction.²³ According to them, social participation is defined as the "person's involvement in activities that provide interaction with others in society or the community".^{23(p.2148)} Various studies in the field of gerontology have been using different concepts with comparable definitions, such as social connectedness²⁴ or social

engagement.¹⁴ Despite the indistinct use of these closely-related concepts, researchers agree on the potential benefits of psychosocial interventions in terms of (1) reducing social isolation or feelings of loneliness,^{3,8,25} (2) increasing well-being by fulfilling social needs,^{26,27} or (3) reducing mild cognitive impairment (MCI) and dementia risk.¹³ Furthermore, several systematic reviews have highlighted the potential of technological interventions in enhancing the social participation of older adults.^{24,28-30} Especially during the COVID-19 pandemic, the role of technological interventions has become crucial in preventing social isolation and loneliness.³¹

Despite the vulnerability of people with dementia for social isolation, and their essential need for social contacts, very little attention has been paid to the effects of technological interventions that target social participation in this population.^{32,33} To date, only one systematic review that explored the effects of ICT-based applications on the social participation of people with dementia could be identified.³⁴ The review includes different types of technology, such as electronic tagging technology, smart homes, and regular computers. The results of this systematic review indicate that technological solutions could facilitate and enhance social participation. Nevertheless, only two of the included studies had used a quantitative control group design, and the overall methodological quality of the included studies was – according to Pinto-Bruno et al. – poor.³⁴ In addition, the review covered literature published up to May 2016. It is likely that new technological interventions have been developed in the past five years, given the rising digital literacy among older adults.³⁵ As such, it is important to keep abreast of the developments. Since this review had a specific focus on people with dementia who live in residential care facilities, it is still unclear how technological interventions influence the social participation among older adults with dementia living in the community.

The present systematic review aims to provide a comprehensive overview of the effects of technological interventions that address social participation in community-dwelling older adults with dementia. In this paper, the definition of social participation by Levasseur et al.²³ will be used. Due to limited studies that directly target people with dementia, this systematic review included studies targeting older adults *with and without* dementia in order to provide a broader scope. Therefore, the following research questions were formulated: (1) what technological interventions have been studied that address the social participation of community-dwelling older adults with and without dementia, and (2) what are their effects and elements of success? It is anticipated that this research will contribute to a better understanding of technological interventions that have been studied and their role in enhancing social participation in community-dwelling older adults with and without dementia.

MATERIALS AND METHODS

This systematic review was registered in the International Prospective Register of Systematic Reviews (PROSPERO) (registration number: CRD42020206654). It followed the procedures for systematic review reporting as stated by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.³⁶

Search Strategy

In June 2020, the five electronic databases Medline (PubMed), PsycINFO, CINAHL, Web of Science, and the Cochrane Library were systematically searched. During the development of the search strategy, it was discovered that there are only limited studies referring to people with cognitive impairment. Consequently, the search was extended to studies that evaluated a technological intervention related to the social participation of community-dwelling older adults *with and without* cognitive impairment. The last search was conducted on 22 June 2020. In a later stage, citation tracing was used to identify additional studies from the reference lists of included studies and relevant systematic reviews.^{24,28-30,37}

The search strategy was based on the PICO model. It included synonyms of the following three categories: “older adults” (population), “technology” (intervention), and “social participation” (outcome). The search strategy used a combination of free text words with Medical Subject Headings (MeSH), Thesaurus terms, or CINAHL Subject Headings. It covered studies published between January 2000 and June 2020. The strategies for each of the electronic databases were developed and conducted by the first reviewer, discussed with the research team, and peer reviewed by an expert scientific information specialist of the Maastricht University Library. The full electronic search strategy conducted in Medline (PubMed) is displayed in Table 1.

Table 1. Full search strategy of electronic database Medline (PubMed).

Categories	Search Terms
#1 Population synonyms	Middle Aged [MeSH] OR middle aged [title/abstract] OR Aged [MeSH] OR aged [title/abstract] OR elderly [title/abstract] OR older adults [title/abstract]
#2 Intervention synonyms	Technology [title/abstract] OR technological [title/abstract] OR technologies [title/abstract]
#3 Outcome synonyms	Community Participation [MeSH] OR community participation [title/abstract] OR Social Participation [MeSH] OR social participation [title/abstract] OR Interpersonal Relations [MeSH] OR interpersonal relations [title/abstract] OR Social Isolation [MeSH] OR social isolation [title/abstract] OR social health [title/abstract] OR social activity [title/abstract] OR social activities [title/abstract] OR social interaction [title/abstract]
Limiters	Results by year: from 2000–2020
#4 Combination of categories	#1 AND #2 AND #3

Eligibility criteria

Studies had to meet the following study characteristics to be included in the systematic review: (1) reported the effects of a technological intervention (no design restrictions imposed), (2) were aimed at community-dwelling older adults (defined as aged 55 and older) with or without cognitive impairment, (3) targeted social participation (defined as a “person’s involvement in activities that provide interaction with others in society or the community”)^{23(p.2148)} and/or social isolation, or reported effects related to social participation/social isolation, and (4) reported at least one outcome related to older adults with or without cognitive impairment. In order to ensure the accessibility of the systematic review findings within the international scientific community, only studies written in English were included. Furthermore, studies had to be published in 2000 or later to be included in the present review.

Study Selection

Two reviewers screened independently the titles and abstracts (P.H. and L.M.M.B.) and the full-texts (P.H. and W.Q.K.) of identified records, using a screening tool based on the eligibility criteria (see Appendix 1). Discrepancies regarding the inclusion of full-text records were discussed with a third reviewer (M.E.d.V.) and resolved by consensus. If multiple reports of the same study were included in the systematic review, they were treated as a single study, after comparing for any discrepancies. The reference lists of included full-text records were screened by the first reviewer in order to possibly include additional studies. The records identified through citation tracing followed the same screening process as the records identified through the electronic search strategy.

Data Extraction

Data extraction of the included full-text records was performed by the first reviewer and checked by a second reviewer. Discrepancies regarding the extracted data were discussed between the two reviewers and resolved by consensus. The data extraction form (see Appendix 2) was developed by the first reviewer and discussed with the research team. The form was pilot-tested on five randomly selected full-text records and subsequently adapted. When additional information or clarification regarding study data was required, the corresponding author of the study was contacted by mail.

Information relating to the general study characteristics was extracted, such as the country of data collection, the study aim, the study design, and the study population. To gain insight into the effects of technological interventions, information about the study outcomes (definition of outcomes, time points measured, outcome measures, and their validity), as well as the main findings/conclusions, was extracted. Detailed information

about the intervention was also extracted. This information included the aim, duration, timing, providers, setting, and theoretical basis of the intervention. In addition, text passages were extracted that possibly indicated factors explaining the success or failure of the technological intervention in influencing social participation.

Data Synthesis

Due to the heterogeneity of study designs, types of technologies, structure of interventions, and outcome measures of included studies, a quantitative synthesis of results was not appropriate. Therefore, a narrative synthesis was conducted to summarize the findings of included studies using descriptive tables and textual descriptions.³⁸

Quality Assessment

Two reviewers (P.H. and W.Q.K.) independently assessed the methodological quality of the included studies, discussed their individual ratings, and agreed on a final rating. Three different quality assessment tools were used, based on the study design of the included studies: quantitative, qualitative, or mixed methods. The kappa coefficients (κ) for the individual ratings of each assessment tool were calculated to determine the inter-rater agreement.³⁹

Given the variety in study design of included quantitative studies, the Effective Public Health Practice Project (EPHPP) tool was used to rate their methodological quality and to assess the risk of bias at the study level.⁴⁰ The tool consists of six component ratings, stimulating the reviewer to critically reflect whether: (1) study participants were representative of the study population, (2) randomization was used, (3) relevant confounders were described and controlled, (4) outcome assessor(s) and study participants were blinded, (5) data collection tools were shown to be valid and reliable, and (6) withdrawals and drop-outs were reported. The rating of each component (i.e., strong, moderate, or weak) was facilitated by a dictionary and led to an overall rating of the methodological quality (i.e., strong, moderate, or weak).

To appraise the methodological quality of included qualitative studies, a checklist based on the quality criteria synthesized by Walsh and Downe⁴¹ was used. These quality criteria were chosen for their detailed description and their coverage of the concept of trustworthiness in qualitative research as defined by Lincoln and Guba⁴². Within the checklist, each of the 12 criteria was rated (i.e., criterion met, criterion partly met, or criterion unmet), covering the following categories: scope and purpose, design, sampling strategy, analysis, interpretation, reflexivity, ethical dimensions, and relevance and transferability. In a next step, points were awarded for each rated criterion (i.e., criterion met = 1 point, criterion partly met = 0.5 points, criterion unmet = 0 points). By adding

up the points, an overall rating of the methodological quality with a maximum of 12 points was determined.

Studies in this systematic review were considered as mixed methods studies as long as a combination of qualitative and quantitative data collection and analysis procedures was described. Based on the recommendations of Heyvaert et al.⁴³, the methodological quality of mixed methods studies was appraised using the EPHPP tool for the quantitative part of the study, the quality criteria by Walsh and Downe for the qualitative part of the study, and the mixed methods criteria by Creswell and Plano Clark to evaluate the integration of both parts.⁴⁴ The latter consists of four criteria that evaluate whether: (1) the collection and analysis of quantitative and qualitative data were rigorous, (2) the integration of both data types was included in the results section, (3) the mixed methods research design was chosen logically, and (4) the mixed methods design was surrounded by theory and philosophy. Each of the four criteria was rated (i.e., criterion met, criterion partly met, or criterion unmet). Points were assigned for each rating (i.e., criterion met = 1 point, criterion partly met = 0.5 points, criterion unmet = 0 points), leading to an overall rating of the methodological quality with a maximum of 4 points.

RESULTS

Study Selection

Figure 1 visualizes the study selection process based on the PRISMA guidelines.³⁶ The database search yielded 2913 records. After title and abstract screening, 79 of the 107 screened full-text records were excluded based on various reasons (see Figure 1). Next to the database search, 9 additional full-text records were identified through citation tracing. Two reports of the same study were identified and treated as one single study. As such, a total of 37 reports, covering 36 studies, met all of the inclusion criteria and were subsequently included in this systematic review.

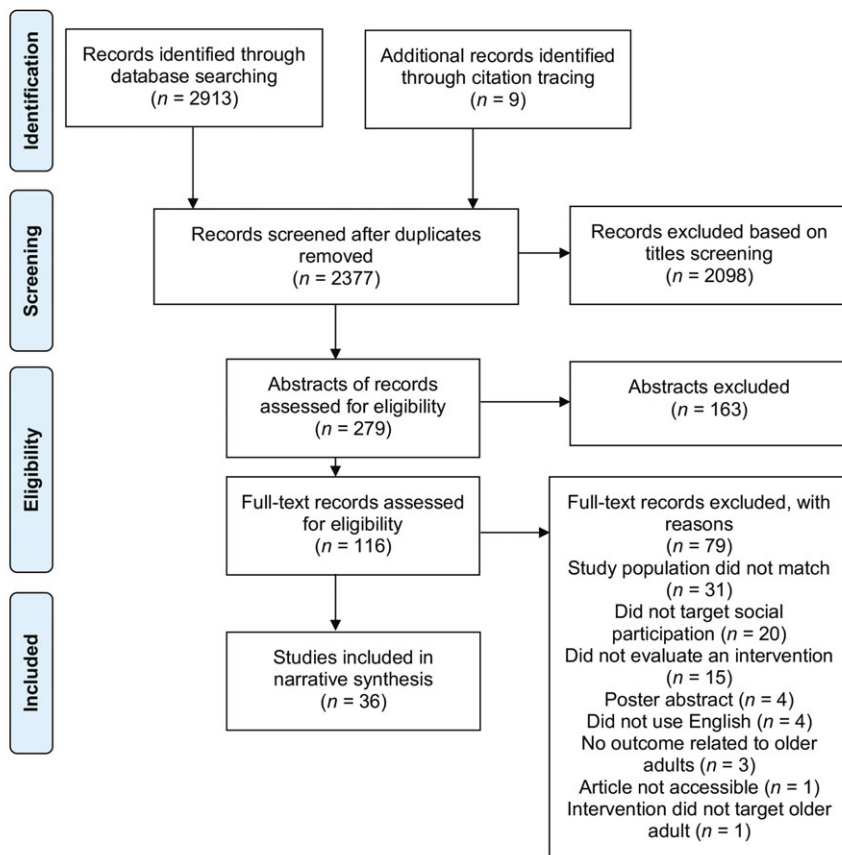
Characteristics of Examined Studies

General Study Characteristics

Studies were published between 2005 and 2020. While 12 studies were published before or in the year 2015,⁴⁵⁻⁵⁶ 24 studies were published after the year 2015.⁵⁷⁻⁸⁰ Studies were conducted in 11 different countries, with most of them being conducted in the USA ($n=17$). The majority of the included studies used a qualitative study design ($n=14$).^{45,47-49,57,59-62,66,68,69,75,76} Of the remaining studies, 12 were of quantitative

nature,^{46,52,55,56,63,65,67,71,73,74,78,80} and 10 studies were considered as mixed methods studies.^{50,51,53,54,58,64,70,72,77,79}

Figure 1. Study selection flowchart based on PRISMA guidelines.



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Study Population Characteristics

Sample sizes (M = 53.86, SD = 72.23) ranged from 5⁵⁷ to 300⁶³, with a majority of the participants being female. While most studies targeted older adults in general (with and without cognitive impairment), one third of the studies excluded older adults with cognitive impairment. Only three of the included studies evaluated the effect of technology on older adults with dementia: two qualitative studies^{62,76} and one quantitative⁷⁸. Next to that, one study⁶⁹ focused on low-income older adults. Several studies additionally evaluated the perceptions of other stakeholders: informal caregivers,^{48,76,78} family members,^{49,79} friends,⁷⁹ volunteers,^{57,68} service coordinators,⁵⁷ and young adult mentors.⁵⁹

Intervention Characteristics

Studies were heterogeneous in terms of intervention characteristics. A third of the included studies ($n=12$)^{45-47,49,51,54,57,61,66,68,73,79} focused on communication and social networking technology, and 10^{55,56,58-60,64,69,70,72,74} evaluated ICT training programs. Interestingly, the more recently published studies that evaluated these ICT training programs incorporated the concept of “reverse mentoring”^{59,70,72}. Within this concept, young adults or students act as mentors and training instructors for older adult participants. Few studies addressed mobile applications ($n=4$)^{65,67,78,80} and gaming technology ($n=4$)^{52,62,75,76}. The remaining studies examined the effect of activity-based musical engagement with iPads,⁵⁰ a tablet-based language training program,⁷⁷ the provision of Internet access,⁵³ technology-assisted self-monitoring of physical activity,⁷¹ a Personal Reminder Information and Social Management (PRISM) system,⁶³ and telecare.⁴⁸

In addition to the various types of technological interventions, the modality and aim of technological interventions varied as well. While 22 technologies included some kind of face-to-face contact, 14 technologies were fully virtual in nature.^{46,48,49,51,53,54,57,61,63,65,66,68,75,79} Only 2^{64,67} of the 36 included studies highlighted an explicit primary intervention aim to increase social participation. Nonetheless, numerous^{47,51,54,56,57,65,70-72,74,75,79} studies mentioned addressing other social outcomes, such as social isolation and loneliness. Although some of the remaining studies ($n=7$) stated non-social intervention aims, such as improving cognitive function or increasing comfort with technology, more than half of them ($n=15$)^{45,49,50,52,53,55,58-63,66,68,77} did not explicitly state an intervention aim at all.

Outcomes Related to Social Participation

Different variables were used to assess the effects of technological interventions on social participation outcomes. Loneliness was the most frequently measured psychosocial outcome identified in quantitative and mixed methods studies,^{46,51,52,54-56,63,65,67,70,72-74,77,80} followed by perceived social support^{56,63,73,74,80} and social isolation.^{50,63,70,74} Interestingly, the variables of loneliness, social isolation, and (perceived) social support were not measured coherently. While most of the studies measured loneliness as a distinct variable, Lee and Kim⁷⁰ measured loneliness together with perceived social support as part of the concept of social isolation. Slegers, van Boxtel, and Jolles⁵⁵ assessed loneliness combined with the frequency and nature of the participants’ social network to evaluate the concept of “social well-being”.

Less frequently measured outcomes included social network size,⁶³ social integration,⁷³ social connectedness,^{53,79} and social interaction.^{71,78} Only one study explicitly stated social participation as quantitative outcome of interest. Emas et al.⁶⁴ used self-developed scales to assess social participation, defined in their study as the participants’ skill ability and confidence level in iPhone/iPad use. While the majority of

included studies assessed the psychosocial outcomes at pretest and posttest, four studies assessed the outcomes one to three months after the intervention.^{51,56,72,74}

Quality Assessment

There was substantial agreement ($\kappa = 0.699$) between the two reviewers for the quality appraisal of quantitative studies before consensus was reached on the final rating.³⁹ Three quantitative studies^{55,63,78} were rated as strong; three^{71,73,80} were rated as moderate; and six^{46,52,56,65,67,74} were rated as weak. From the data in Table 2, it is apparent that the quality of most study designs was strong. Eight^{46,52,55,56,63,71,78,80} of the quantitative studies were at first considered as Randomized Controlled Trials (RCTs). However, three studies did not describe the randomization procedure in their study methodology.^{46,52,56} According to the EPHPP guidelines, these studies were classified as Clinical Controlled Trials (CCTs). One additional study was classified as a CCT because the randomized allocation of study participants conflicted with participants' availability. The remaining quantitative studies were classified as single-group cohort studies.^{65,67,74}

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Table 2. Quality appraisal of quantitative studies (EPHPP) ($n=12$).

Study	Selection Bias	Study Design	Confounders	Blinding	Data Collection Methods	Withdrawals and Drop-Outs	Global Rating
78	2	1	1	2	1	1	1
55	2	1	1	3	1	1	1
63	2	1	1	2	1	2	1
71	3	1	1	2	1	1	2
73	3	1	1	2	1	1	2
80	3	1	1	2	1	1	2
46	2	1	3	3	1	1	3
56	3	1	1	3	3	2	3
52	3	1	3	3	3	1	3
67	3	2	3	3	3	1	3
74	3	2	3	3	1	3	3
65	3	3	3	3	3	1	3

Notes: 1 = strong, 2 = moderate, 3 = weak. Studies are named according to their reference number within this systematic review.

Several study aspects led to a lower methodological quality rating among quantitative studies. Overall, these studies were subjected to a high chance of selection bias. Only one study⁵⁵ had a likely representative study sample. Moreover, most included

studies did not specify in most cases the percentage of selected individuals that agreed to participate in the study. In addition, several studies ($n=6$) did not mention about the blinding of outcome assessors.

For the methodological quality ratings of qualitative studies, a kappa coefficient (κ) of 0.415 was achieved, which indicated a moderate agreement between the two reviewers before consensus was reached on the final rating.³⁹ Table 3 shows a detailed overview of the individual criteria ratings and total ratings assigned for the methodological quality of included qualitative studies. The final ratings ranged from 5.5⁶⁰ to 9^{66,76} out of 12. In general, included studies clearly stated their research aims or questions and were thoroughly contextualized by existing literature. However, a majority of the qualitative studies did not discuss the relationship between researcher and study participants nor the potential influence of researchers on the research process. Some studies did not provide a justification for the chosen sampling methods and the analytic approach used.

The kappa coefficient (κ) for the quality assessment of mixed methods studies equalled 0.617, which indicated a substantial agreement between the two reviewers before consensus was reached on the final rating.³⁹ The methodological quality ratings of mixed methods studies are displayed in Table 4. What stands out in the table is that both the quantitative and mixed methods final ratings indicate a weak methodological quality. None of the studies framed the mixed methods procedures within theory and philosophy. Moreover, most mixed methods studies did not integrate the qualitative and quantitative data strands. The qualitative final ratings ranged from 4 to 9 out of 12. Only a limited number of mixed methods studies discussed choices and procedures concerning qualitative sampling, data collection, and analysis in detail.

Table 3. Quality appraisal of qualitative studies (Walsh and Downe criteria)(n = 14).

Criteria	66	76	61	45	47	48	59	68	69	75	62	57	49	60
Clear statement of, and rationale for, research question/aims/purposes	+	+	+	+	+	+	+	+	+	+	+	±	±	±
Study thoroughly contextualized by existing literature	+	+	±	+	+	±	+	+	+	+	+	+	+	+
Method/design apparent and consistent with research intent	+	±	±	±	+	±	±	-	±	-	±	±	±	±
Data collection strategy apparent and appropriate	±	+	+	±	+	+	±	±	±	±	±	±	±	±
Sample and sampling method appropriate	±	±	±	±	±	±	±	+	±	±	±	-	±	±
Analytic approach appropriate	±	±	±	±	-	±	±	±	±	±	±	±	-	±
Context described and taken account of in interpretation	+	+	±	±	±	±	±	+	+	+	±	±	±	±
Clear audit trail given	±	+	+	±	±	±	±	±	±	±	±	±	±	-
Data used to support interpretation	+	±	+	±	±	+	+	+	±	+	+	+	±	±
Researcher reflexivity demonstrated	-	±	-	±	+	±	-	-	-	-	-	-	±	-
Demonstration of sensitivity to ethical concerns	+	±	±	±	-	±	±	-	±	±	±	±	±	±
Relevance and transferability evident	+	+	+	+	±	±	+	+	+	+	±	+	±	±
Total score	9	9	8	7.5	7.5	7.5	7.5	7.5	7.5	7.5	7	6.5	6	5.5

Notes: +, criterion met (= 1 point), ±, criterion partly met (= 0.5 points), -, criterion unmet (= 0 points). By adding up the points, a total score of the methodological quality with a maximum of 12 points was determined. Studies are named according to their reference number within this systematic review.

Effects of Interventions on Social Participation

Quantitative Findings

Table 5 synthesizes the findings of each included quantitative study, listed in descending order based on their methodological quality. Very few of the quantitative studies found statistically significant effects on social participation outcomes. Only one quantitative study⁷⁸ could be identified that addressed exclusively community-dwelling older adults with dementia.

Three quantitative studies with a strong methodological quality rating did not find significant group differences at post-intervention follow-up. In the study by Slegers,

van Boxtel, and Jolles⁵⁵, no significant intervention effect on social well-being or any other dimension of well-being could be identified. In contrast, in the study by Czaja et al.⁶³, significant changes between the two groups in the domains of loneliness and perceived social support were identified at mid-term follow-up. In addition, a decrease in social isolation could be found. Similarly, in the RCT by Yu et al.⁷⁸, outcomes related to social participation significantly improved at mid-term follow-up. While there were no significant differences between the three group in the primary outcome “mood”, there was a significant higher social interaction in the intervention group compared with the control and comparison group at 6 weeks. However, the significant group differences at mid-term follow-up reported in these two latter studies^{63,78} could not be maintained at post-intervention follow-up.

Six^{46,56,67,71,73,74} of the remaining nine quantitative studies failed to demonstrate statistically significant intervention effects on social participation outcomes in the intervention group. It has to be noted that a majority of these studies were feasibility trials.^{46,67,71,74} Two technological interventions^{71,73} did not focus on outcomes related to social participation as a primary aim. Both studies found statistically significant effects on their primary outcomes of interest: physical activity⁷¹ and cognitive function⁷³. Of the three quantitative studies that reported statistically significant changes in social participation outcomes, two reported a significant decrease in loneliness among older adults.^{52,65} Moreover, one study⁸⁰ found a significant interaction effect for informational and tangible support.

Qualitative Findings

Synthesized information about the intervention, design, and main findings of included qualitative studies can be found in Table 6, sorted in descending order based on the studies’ quality assessment rating. Qualitative studies reported various benefits of technological interventions on the social participation of older adults. These benefits included: (1) maintenance or development of social relationships or connections,^{47,48,57,59,66,68,69} (2) improvements in social connectedness,^{49,60} (3) decrease in loneliness,^{45,57} (4) companionship and social interaction,⁶¹ and (5) improvements in communication.⁶⁸ In addition, study participants reported benefits of technological interventions in terms of life satisfaction,⁶⁰ ICT skills,⁴⁷ confidence in the use of technology,⁵⁹ or physical activity.⁶¹ Only two qualitative studies^{62,76} focused on community-dwelling older adults with dementia.

Mixed Methods Findings

A summary of findings from mixed methods studies is detailed in Table 7. Less than half of the studies revealed significant intervention effects on social participation outcomes. One study⁶⁴ found a significant increase in social participation among older adult participants. In this study, social participation was measured as the participants' skills ability and confidence level in several ICT-related tasks. Furthermore, three studies^{54,70,72} reported a statistically significant decrease in loneliness. In addition to this, Lee and Kim⁷⁰ also found a decrease in total social isolation. The remaining six mixed methods studies did not find any statistically significant intervention effects on social participation outcomes.^{50,51,53,58,77,79} All of them were carried out with small sample sizes and five of them were described as pilot studies.^{50,51,53,58,77,79}

Based on qualitative findings, study participants reported overall positive effects on social participation, such as enhanced social connectedness^{53,72} and enhanced ICT skills that facilitated the communication with loved ones⁶⁴. While one study⁵⁰ found that participants in a group intervention developed social cohesion and group identity, two other studies^{51,77} found that participants in group intervention programs had a lack of group cohesion and social ties.

Table 4. Quality appraisal of mixed methods studies (EPHPP, Walsh and Downe criteria, and Creswell and Plano Clark criteria)(*n* = 10) .

Assessment Tools								
	EPHPP	Selection bias			Study design			
51		3				1		
77		3				2		
70		2				2		
72		3				3		
50		3				1		
79		3				2		
58		2				2		
53		3				2		
54		3				2		
64		3				2		
	Qualitative criteria	Study purpose	Study scope	Study design	Data collection	Sampling strategy	Analysis	Study context
51		+	±	±	+	±	±	+
77		+	±	±	+	±	±	±
70		±	±	-	±	±	±	+
72		+	+	±	±	±	±	±
50		+	±	-	±	±	±	-
79		+	+	±	±	±	-	±
58		+	±	-	±	±	±	±
53		+	+	±	±	-	-	-
54		+	+	-	±	±	-	±
64		+	±	-	±	±	-	±
	Mixed methods criteria	Frames the procedures within theory and philosophy			Organizes the procedures into specific research designs			
51			-			±		
77			-			±		
70			-			±		
72			-			±		
50			-			±		
79			-			-		
58			-			±		
53			-			±		
54			-			±		
64			-			±		

Notes: EPHPP: 1 = strong, 2 = moderate, 3 = weak; Qualitative criteria: +, criterion met (= 1point); ±, criterion partly met (= 0.5 points); -, criterion unmet (= 0 points). By adding up the points, a total score of the methodological quality with a maximum of 12 points was determined; Mixed methods criteria: +, criterion met (=1point); ±,

Criteria					
Con-founders	Blinding	Data collection methods		Withdrawals and drop-outs	Final rating
1	3	1		2	3
3	3	1		3	3
3	3	3		3	3
3	3	3		3	3
3	3	1		1	3
3	3	3		1	3
3	3	3		3	3
3	3	1		2	3
3	3	3		3	3
3	3	3		3	3
Audit trail	Data to support interpretation	Reflexivity	Ethical dimensions	Transferability	Final rating
+	±	±	+	+	9
±	+	-	±	±	7
±	+	-	±	+	6.5
±	-	-	±	±	6
±	±	±	±	±	5.5
±	±	-	-	±	5.5
-	±	-	±	±	5
-	±	-	±	±	4.5
-	-	-	±	±	4.5
-	±	-	-	±	4
Collects and analyses both qualitative and quantitative data rigorously			Intention-ally integrates the two data strands		Final rating
	±		-		1
	±		-		1.5
	±		-		1
	±		-		1
	±		±		1.5
	±		±		1
	±		-		1
	±		±		1.5
	±		-		1
	±		-		1

criterion partly met (= 0.5 points); -, criterion unmet (= 0 points). By adding up the points, a total score of the methodological quality with a maximum of 4 points was determined. Studies are named according to their reference number within this systematic review.

Table 5. Design, methods, and findings related to social participation reported from included quantitative studies.

Authors (Year), Country	Study Design¹	Experimental Intervention	Control or Comparison Intervention	Setting
Yu et al. (2019), ⁷⁸ USA	RCT ²	Mobile reminiscing therapy app "Memory Matters": one-on-one 30 min sessions with an interventionist (2x/week) for 6 weeks followed by independent use for 6 weeks	Comparison: group 30 min sessions with an interventionist (2x/week) followed by group 30 min sessions with an activity director. Control: waitlist.	Older adults' residence
Slegers, van Boxtel, and Jolles (2008), ⁵⁵ the Netherlands	CCT ³	Computer training program: 3x 4 hr training sessions for 2 weeks, independent use of the computer combined with assignments (1x/2 weeks in the first 4 months, 1x/month for the last 8 months)	Comparison: 3x 4 hr training sessions for 2 weeks, followed by independent computer use. Control: No intervention.	Home-based (setting of training sessions not mentioned)
Czaja et al. (2018), ⁶³ USA	CCT	Personal Reminder Information and Social Management (PRISM) system: use of the computer system for 12 months	Comparison: use of a notebook with printed content (similar to PRISM) for 12 months.	Home-based
Matz-Costa et al. (2018), ⁷¹ USA	RCT	Engaged4Life program: (1) technology-assisted self-monitoring of physical activity for 8 weeks, (2) 3 hr psycho-education group session, (3) phone calls by peer mentors for 2.5 weeks (2x/week)	Comparison: technology-assisted self-monitoring of physical activity for 8 weeks.	Home-based
Myhre, Mehl, and Glisky (2017), ⁷³ USA	CCT	Facebook: 2 hr training sessions for 1 week (3x/week), use of Facebook (1x/day) and writing posts (1x/week) for 7 weeks	Comparison: online diary website. 2 hr training sessions for 1 week (3x/week), use of diary website (1x/day) and writing data entries (1x/week) for 7 weeks. Control: waitlist.	Home-based combined with training sessions at computer lab classrooms
Vanoh et al. (2019), ⁸⁰ Malaysia	RCT	WESIAT 2.0© (https://creativecommons.org/licenses/by-nc/3.0/ , accessed on 14 April 2021) web-based wellness application: use of the application for 6 months, 30 min/day (4x/week) in combination with group counselling sessions in the first 3 months	Use of a health education pamphlet containing dietary recommendations for 6 months, in combination with dietary counselling.	Home-based combined with counselling sessions at a community hall
Bickmore et al. (2005), ⁴⁶ USA	CCT	Embodied Conversational Agent (ECA) "FitTrack": daily interaction with the relational agent (who acted as an exercise advisor) for 2 months	Comparison: physical activity intervention for 2 months.	Home-based

Participants (n = Sample Size)	Outcomes Related to Social Participation	Outcome Measures Related to Social Participation	Findings Related to Social Participation
Older adults with (n = 80) dementia and caregivers	Social Interaction (pretest, 6 weeks, posttest)	Pleasant Events Schedule-AD (PES-AD short version)	6 weeks: significant higher social interaction of the individual MM group vs. the comparison ($t = 2.38, p = 0.017$) and the control group ($t = 2.48, p = 0.005$). 12 weeks: not maintained.
Older adults without cognitive impairments (n = 236)	Social well-being (pretest, 4 months, posttest)	De Jong Gierveld Loneliness Scale, self-reported nature, and frequency of social network	No significant positive (or negative) intervention effect on social well-being.
Older adults without cognitive impairments (n = 300)	Social isolation, loneliness, perceived social support, and social network size (pretest, 6 months, posttest)	Friendship Scale, UCLA Loneliness Scale, Interpersonal Support Evaluation List, and Lubben Social Network Index	6 months: significant decrease in loneliness ($b = 1.72, p < 0.04$) and increase in perceived social support ($b = -1.96, p < 0.04$) of the PRISM group vs. comparison group. 12 months: not maintained.
Older adults without cognitive impairments (n = 30)	Social interaction (pretest within first week, week 4)	Survey related to the quantity and quality of social interaction	No significant changes in social interaction of the intervention group vs. comparison group.
Older adults without cognitive impairments (n = 43)	Loneliness, social support, and social integration (pretest, posttest)	UCLA Loneliness Scale, Medical Outcomes Study Social Support Survey, Lubben Social Network Scale, and Social Provisions Scale	No significant differences in social support, loneliness, and social integration (pretest vs. posttest) in any of the groups.
Older adults without cognitive impairment (n = 60)	Loneliness and social support (pretest, 3 months, posttest)	Three-item loneliness scale and Medical Outcome Social Support Survey (MOSS)	Significant interaction effect for informational support ($\eta^2_p = 0.123, p < 0.05$) and tangible support ($\eta^2_p = 0.186, p < 0.01$). No statistically significant interaction effects for loneliness and other dimensions of social support.
Older adults without cognitive impairments (n = 21)	Loneliness (pretest, posttest)	R-UCLA Loneliness Scale	Loneliness decreased statistically significant in the control group, (paired $t(7) = 2.74, p < 0.05$) not in the intervention group. No significant group differences.

Table 5. Table 5. Continued.

Authors (Year), Country	Study Design¹	Experimental Intervention	Control or Comparison Intervention	Setting
Woodward et al. (2011), ⁵⁶ USA	CCT	Computer/Internet training program: 11 training sessions in a group delivered by the project coordinator for 6 months (1x/2weeks)	Control: no intervention.	Computer lab
Kahlbaugh et al. (2011), ⁵² USA	CCT	Playing Wii: 1 hr activity with an undergraduate student for 10 weeks (1x/week)	Comparison: 1 hr watching television with an undergraduate student for 10 weeks (1x/week). Control: no visit.	Home-based
Jansen-Kosterink et al. (2020), ⁶⁷ the Netherlands	Cohort	Mobile application “GezelschApp” that stimulates users to engage in local activities together with other users: use of the application for 3 months combined with tailor-made coaching by a social worker	NA ⁴	Home-based
Neil-Sztramko et al. (2020), ⁷⁴ Canada	Cohort	iPad training program “AGE-ON”: 2 hr education sessions (1x/week) for 6 weeks and use of the iPad/Internet at home	NA	Home-based (setting of training sessions not mentioned)
Goumo-poulos, Papa, and Stavrianos (2017), ⁶⁵ Greece	One group mid- and posttest	Tablet-based intervention “Senior App Suite”: use of the mobile application suite for 8 weeks	NA	Home-based

Notes: ¹Study design as classified by the quality assessment (EPHPP). ²RCT = randomized controlled trial. ³CCT = clinical controlled trial. ⁴NA = not applicable

Participants (n = Sample Size)	Outcomes Related to Social Participation	Outcome Measures Related to Social Participation	Findings Related to Social Participation
Older adults (n = 83)	Social support and loneliness (pretest, 3 months, posttest, 3 months following the training)	Self-reported social network data, Multidimensional Scale of Perceived Social Support (MSPSS), De Jong Gierveld Loneliness Scale	No statistically significant differences in social support and loneliness between the groups. Trend of higher perceived social support in intervention group vs. control group.
Older adults (n = 36)	Loneliness (pretest, posttest)	UCLA Loneliness Scale	Significant decrease in loneliness from pretest to posttest in intervention group ($F(2,30) = 6.24, p < 0.005$), increase in loneliness in comparison group.
Older adults (n = 41)	Loneliness (pretest, posttest)	De Jong Gierveld Loneliness Scale	Loneliness decreased among study participants (pretest vs. posttest). Not statistically significant.
Older adults (n = 32)	Social isolation and loneliness (pretest, posttest), social support (pretest, posttest, 1 month following the program)	Duke Social Support Index (DSSI), De Jong Gierveld Loneliness Scale, Lubben Social Network Scale	No significant differences in any social outcome measures.
Older adults without cognitive impairments (n = 22)	Loneliness (pretest, posttest)	R-UCLA Loneliness Scale	"Senior App Suite" may reduce loneliness moderately ($p < 0.034$).

Table 6. Methods and main findings reported from included qualitative studies.

Authors (Year), Country	Technological Intervention	Setting	Participants (n = Sample Size)
Hemberg and Fischer (2018), ⁶⁶ Finland	Real video communication "CaringTV"	Home-based	Older adults (n = 7)
Unbehaun et al. (2018), ⁷⁶ Germany	Exergames program: regular use of the system combined with visits of trained research assistants 2x/week for 8 months	3 domestic environments and 4 day-care centres	Older adults with dementia (n = 14) and caregivers (n = 9)
Chi et al. (2017), ⁶¹ USA	Digital pet avatar: daily interaction with a conversational agent (a cat or dog avatar) for 3 months	Home-based	Older adults without cognitive impairment (n = 10)
Ballantyne et al. (2010), ⁴⁵ Australia	Internet Social Networking Website (ISNW) "About My Age": one-on-one education sessions delivered by project team members for 3 months (in the beginning, weekly support visits, then less frequently)	Home-based	Older adults (n = 6)
Biniok and Menke (2015), ⁴⁷ Germany	Tablet with communication platform "SONIA": training sessions in groups delivered by researchers and volunteers and use of the platform for 6 months	Home-based combined with training sessions at a university/community college	Older adults (n = 30)
Bowes and McColgan (2012), ⁴⁸ UK	Telecare	Home-based	Older adults (n = 76) and family caregivers (n = 16)
Breck, Dennis, and Leedahl (2018), ⁵⁹ USA	Cyber-Seniors Program: technology training lessons delivered by young adult mentors using reverse mentoring 1x/week	Senior centre and other locations	Older adults (n = 29) and young adult mentors (n = 28)
Judges et al. (2017), ⁶⁸ Canada	Digital communication tool "InTouch": social contact using the system with a paired volunteer 1x/week for 3 months	Home-based	Older adults (n = 10) and volunteer participants (n = 10)
Kim and Gray (2016), ⁶⁹ USA	Computer training program: use of computer and 1 hr training sessions of computer/Internet skills (1x/week)	Home-based combined with training sessions at senior housing facilities	Low-income older adults (n = 11)

Data Collection Methods	Main Findings
Interviews	Overarching theme: "Being in a movement toward becoming a unity as human being". ^{66(p.93)} Technology facilitated making new experiences, dedicating new meaning to everyday life, and maintaining or developing social contacts/relationships. Welfare technology as: "a window toward the world". ^{66(p.93)}
Semi-structured interviews and ongoing evaluation of the prototype	Benefits for people with dementia: enhanced physical skills, increased motivation, showed learning effects, increased social interaction and sense of interpersonal relationships (in day-care home setting), improved daily life routine. Benefits for caregivers: relief for caregivers (e.g., freeing up time).
Secondary analysis of semi-structured interviews	Benefits: provided companionship, reminders, a journal, entertainment, increased social interaction and physical activity. System challenges: technical issues and the limited ability to make conversations. Major concerns: privacy, costs, and dependence.
Semi-structured interviews and reflective journals of the project team	Benefits: enabled exploration of other ways of communication, contributed to a positive and personalised learning experience (using the one-on-one approach), reduced temporal loneliness (extent varied per case), increased sense of connectivity to the outside world to some extent.
Group discussions and observations	ICT created, extended, and facilitated engagement in participation space: Participants with few social contacts: enhanced technological skills, increased self-esteem, and increased social participation. Socially active participants: growth and intensification of social contacts/interactions. Some participants (mostly with high technological skills): only slight changes in social participation.
Semi-structured interviews	Independence: promoted participants' confidence, feelings of safety, and freedom. Social Participation: enabled living in the community, enhanced relationships, but led to restriction in activities formerly enjoyed and narrowing of social networks. Identity: contributed to a positive sense of identity.
Session logs of young adult mentors and surveys	Benefits for older adults: gained confidence in the use of technology to make social connections digitally. Benefits for young adult mentors: enhanced leadership skills. Both: Age-related stereotypes were challenged. Intergenerational engagement and connections emerged.
Semi-structured interviews, field notes of volunteer participants and the study coordinator, and data logs	Benefits: improved communication and positive changes in relationships. Use of technology led to mixed feelings in study participants. Adoption: 4 of the study participants were able to adopt "InTouch". Internal motivation contributed to successful adoption. Key barriers to adoption: lack of volunteer support, social difficulties, and diverse health issues.
Semi-structured interviews and interviewer's field notes	Benefits: enhanced social connections, monetary benefits, and development of life skills. Barriers to program participation: fear of technology, low literacy, and distrust of governmental programs. Barriers to sustained Internet use: problems and costs of broadband services, concerns about cyber security, and limited proficiency. Success factors to sustained Internet use: ongoing technical support and individual ICT devices.

Table 6. Continued.

Authors (Year), Country	Technological Intervention	Setting	Participants (n = Sample Size)
O'Brien, Smith, and Beck (2016), ⁷⁵ USA	3D virtual world "Second Life" (SL): training/onboarding for two weeks, SL events organized by trained staff for 8 weeks, independent use of SL for 2 weeks	Home-based	Older adults (n = 51)
Cutler, Hicks, and Innes (2015), ⁶² UK	Digital gaming training program: 2 hr training sessions ("Tech Clubs") in groups delivered by facilitators for 6–8 weeks	Home-based combined with training sessions at 4 different venues	Older adults with dementia (n = 29)
Airola, Rasi, and Outila (2020), ⁵⁷ Finland	Phone and video conferencing (VC) service: calls from a volunteer 1x/week	Home-based	VC service coordinator, volunteers, and older adult service users (n = 5)
Cornejo, Tentori, and Favela (2013), ⁴⁹ Mexico	Ambient Social Network System "Tlatoque": use of an interactive display for 21 weeks	Home-based	Older adults (n = 2) and family members (n = 30)
Burmeister et al. (2016), ⁶⁰ USA	iPad training program: 2 hr training sessions in groups delivered by a peer trainer 1x/week for 4 months	Home-based combined with training sessions at a Seniors Citizen's Club	Older adults (n = 6)

Table 7. Design, methods, and findings related to social participation reported from included mixed methods studies.

Authors (Year), Country	Experimental Intervention	Setting	Participants (n = Sample Size)
Hind et al. (2014), ⁵¹ UK	One-on-one telephone friendship (TF) vs. usual care control: (1) 10 to 20 min calls delivered by volunteer facilitators for six weeks (1x/week), followed by (2) 1 hr TF groups for 12 weeks (1x/week)	Home-based	Older adults without cognitive impairments (n = 157)
Ware et al. (2017), ⁷⁷ France	Language training program: 2 hr sessions of an English language training delivered by a native English-speaking psychologist using a tablet-based multimedia approach for 4 months (1x/week)	Laboratory of a hospital	Older adults without cognitive impairments (n = 14)
Lee and Kim (2018), ⁷⁰ USA	Intergenerational Mentor-Up (IMU) class: six 1 hr one-on-one technology tutorial sessions delivered by college students (partly in groups)	Senior centres and housing facilities	Older adults without cognitive impairments (n = 59)

Data Collection Methods	Main Findings
Semi-structured interviews	Older adults reported to be open to the possibility of creating online relationships within the virtual world. Most of the participants did not succeed in creating them. Obstacles to the formation of online relationships: personality, difficulties with other avatars, and lack of face-to-face interactions.
Ethnographic field notes, self-complete questionnaires, and focus groups	Impact of digital gaming on healthy ageing: promoted lifelong learning; increased physical activity, social interaction, and mental stimulation; and promoted independence.
Semi-structured interviews	Barriers to learning and using the service: technical problems, volunteer–user relationship, lack of technical skills, health status, and a negative attitude toward technology. Enablers to learning and using the service: technical support, social support networks, previous experience with technology, and a positive attitude toward new technologies. Benefits: facilitated to establish networks and reduce loneliness.
Semi-structured interviews and a focus group	Tlatoque supported social connectedness through: a higher frequency of social contacts (consensual meetings or opportunistic encounters around the system). the strengthening of social ties between the older adult and family members.
Interviews, participants' diaries, researchers' observations, and peer trainer's reports	Benefits: enhanced ICT skills, increased social connectedness, and improved life satisfaction. Important factors: individualized education approach and social connections between participants and peer trainer.

Outcomes Related to Social Participation	Quantitative Outcome Measures Related to Social Participation	Qualitative Data Collection Methods	Findings Related to Social Participation
Loneliness (pretest, 6 months follow-up post randomization)	De Jong Gierveld Loneliness Scale	Semi-structured interviews	Loneliness: no statistically significant improvement. Interviews: participant reported a lack of face-to-face contact and a dissatisfaction with group cohesion.
Loneliness (pretest, posttest)	UCLA Loneliness Scale, and semi-structured interviews	Semi-structured interviews	Loneliness: no statistically significant improvement. Interviews: participants reported that they did not build strong social ties with other group participants.
Social isolation (pretest, posttest)	Perceived social isolation measure (loneliness and social support) and self-reported life stressors checklist	Interviews and researchers' field notes	Total social isolation significantly decreased ($t = 3.84, p < 0.001, d = 0.74$), with no significant change in lack of social support and a statistically significant decrease in loneliness ($t = 7.53, p < 0.001, d = 1.45$).

Table 7. Continued.

Authors (Year), Country	Experimental Intervention	Setting	Participants (n = Sample Size)
Mullins et al. (2020), ⁷² USA	Internet Information Station program: three different computer classes delivered by students	Four apartment buildings of a Housing and Urban Development community	Older adults participating in program (n = 262) Older adults filling in the R-UCLA Loneliness Scale (n = 11)
Engelbrecht and Shoemark (2015), ⁵⁰ Australia	Activity-based musical engagement using iPads vs. Traditional Music Instruments (TMI): 1 hr sessions of activity-based musical engagement in groups delivered by a therapist for 5 weeks (1x/week)	Not mentioned	Older adults without cognitive impairments (n = 6)
Zaine et al. (2019), ⁷⁹ UK and Brazil	Human-facilitated social networking system "Media Parcels": use of the tablet-based system facilitated by a clinical psychologist for two weeks with family members (trial 1) or friends (trial 2)	Home-based	Older adults (n = 2), family members (n = 2), and older adult friends (n = 2)
Arthanat, Vroman, and Lysack (2016), ⁵⁸ USA	iPad training program: individualized one-on-one training sessions delivered by a coach (occupational therapy student) for 3 months (1x/month), then iPad use without assistance for 3 months	Home-based	Older adults without cognitive impairments (n = 13)
Mellor, Firth, and Moore (2008), ⁵³ Australia	Providing internet access: use of computer/Internet for 12 months (with support on a daily basis for the first two weeks)	Retirement villages	Older adults (n = 20)
Ring et al. (2015), ⁵⁴ USA	ECA ² motion sensor vs. non-sensor condition: interact with the ECA on a touchscreen computer (1x/day) for 1 week	Home-based	Older adults (n = 14)
Emas et al. (2018), ⁶⁴ USA	iPad/iPhone training program: 1 hr multimodal training sessions in groups 1x/week for 7 weeks	Home-based combined with training sessions at a gated retirement community	Older adults (n = 25)

Notes: ¹Only two of the four categories of ICT activities were relevant: family connections and social connections.

²ECA = embodied conversational agent.

Outcomes Related to Social Participation	Quantitative Outcome Measures Related to Social Participation	Qualitative Data Collection Methods	Findings Related to Social Participation
Loneliness (pretest, posttest at 4–6 weeks after the program)	R-UCLA Loneliness Scale	Ethnographic interviews and observations	Participants reported enhanced social connectedness. Observed increase in participation in the common areas of the Housing and Urban Development community. Decrease in loneliness of the technology class group (vs. baseline group): significant change ($p = 0.023$) on the item “There is no one I can turn to”.
Social isolation (pretest, posttest)	Friendship scale	Journal entries, researcher’s field notes, and session reflections	No significant differences in social isolation (1) between the iPad and the TMI group and (2) within the groups (pre- vs. posttest). Reported benefits for both groups: enhanced positive self-concepts and developed social cohesion and group identity.
Feelings of social connection (pretest, week 1, posttest)	Self-developed Relationship Semantic Differential Scale (RSDS)	Interviews	Participants reported contacting each other more often and feeling closer to each other.
Breadth and frequency of technology use related to social connections (pretest, 1 month, 2 months, 3 months, 4 months, posttest)	Self-developed questionnaire ¹	Field observations, self-developed end-of-study questionnaire, and focus groups	Modest (not significant) increase in activities involving social connections. Participants identified benefits and challenges of the program related to technology experiences, interactions with the coach, the training approach, and specific activities.
Social connectedness (pretest, 3 months, 6 months, 9 months, posttest)	Social Connectedness Scale	Semi-structured interviews	At 12 months: no significant differences in social connectedness. Benefits reported in interviews: positive impact on social connectedness.
Loneliness (pretest, posttest)	UCLA Loneliness Scale	Diary entries and semi-structured interviews	Significant lower loneliness in intervention group vs. comparison group when interacting with the ECA ($F(1,150) = 7,713, p < 0.01$). This indicates that the ECA is more effective in reducing loneliness when using a motion sensor to actively initiate social interactions with older adults.
Participants’ skill ability (PSA); participants’ confidence level (PCL) (pretest, posttest)	Self-developed scales measuring PSA and PCL	Journaling prompts	Statistically significant increase in PSA of defining several Internet acronyms and statistically significant increase in PCL using FaceTime ($t(16) = 6.85, p = 0.00$), and taking photos ($t(16) = 4.26, p = 0.0001$). Facilitation of social participation: participants reported to have gained skills and knowledge in communicating with loved ones using concepts such as FaceTime, texts, e-mails, and phone calls.

DISCUSSION

This systematic review is, to our knowledge, the first to assess the potential of technological interventions in enhancing the social participation of community-dwelling older adults, including people with dementia. The primary aim of this review was to provide a comprehensive overview of technology that has been studied and used to address social participation in this study population. In total, 36 studies were included. A variety of technological interventions were identified, most of them being communication and social networking technology and ICT training programs. These findings correspond with findings from other systematic reviews that looked at the use of technology to address social isolation among older adults in general.²⁸⁻³⁰ Baker et al.³⁰, however, identified pet robots as another technology-based intervention. As pet robot evaluations are mostly conducted in institutional care settings, it is not surprising that none of the included studies evaluated pet robots in community settings.⁸¹

Based on the recency of the studies, we note an apparent shift away from computer-based interventions to more tablet- and smartphone-based interventions. This may be due to a greater ease of access to tablets and smartphones as compared to computer-based solutions since the former options are usually incorporated into one's everyday life. Despite the fact that tablet- and smartphone-based technologies are portable and non-location bound, most studies that used these technologies conducted the interventions in participants' homes. However, prior studies have shown that the engagement in community-based out-of-home activities can contribute to the social participation of older adults.^{82,83} Considering this, it is surprising that only one study used technology to facilitate social participation in the community, by encouraging older adults via the mobile application "GezelschApp" to physically engage in community-based activities with others.⁶⁷ This finding may be explained by the fact that most studies did not have an explicit focus on improving social participation. Instead, their focus was on reducing the negative consequences of social isolation. This highlights the empirical consequences of having a poorly defined concept of social participation.

Effects of Interventions on Social Participation

Overall, quantitative and mixed methods studies showed that the use of technological interventions had limited effects on loneliness, social isolation, and social support. This may be attributed to the fact that many studies were pilot studies with small sample sizes. Nevertheless, qualitative findings were able to identify various benefits, such as the development of social connections and the improvement of social connectedness. As expected, only limited studies addressing people with dementia could be identified ($n = 3$).^{62,76,78} Due to the heterogeneity of study and intervention characteristics and the limited

number of studies that targeted older adults with dementia, no subgroup analyses could be carried out to evaluate whether the effects may differ between people with and without dementia. Based on the body of evidence that has been synthesized narratively, no conclusion can be drawn regarding the effectiveness of technological interventions for people with dementia. Consequently, the present findings suggest that technological interventions may have the potential to alleviate loneliness and enhance social support in cognitively healthy older adults. As the effects on loneliness and social support were inconsistent, findings have to be interpreted with caution.

Such inconsistent findings were also reported in other systematic reviews in similar fields. Although the effects of ICT on loneliness were inconclusive in the review by Chen and Schulz²⁹, ICT was found to positively affect social connectedness, social isolation, and social support. A majority of the studies included in the review by Khosravi et al.³⁰ found positive effects in reducing loneliness or social isolation. These inconsistent study findings may be due to the use of different inclusion criteria. Khosravi et al.³⁰ for example included exclusively quantitative study findings related to a younger age group (older adults aged 50+) living in institutional care or community settings. In contrast, the present systematic review focused on various research designs including older adults aged 55 years or older living in a community setting. Regarding the effectiveness of technology on the social participation of people with dementia, other systematic reviews also failed to identify a high number of studies with rigorous study designs.^{34,37}

Findings of the present systematic review suggest that social interaction, face-to-face contact, and intergenerational engagement may be successful elements of technological interventions in enhancing the social participation in community-dwelling older adults. All seven studies that found a statistically significant intervention effect included a social interaction element.^{52,54,64,65,70,72,80} This finding is not surprising, as social participation in the present review was defined as a “person’s involvement in activities that provide interaction with others in society or the community”.^{23(p. 2148)} Moreover, it is noteworthy that five^{52,64,70,72,80} of the seven studies had the element of a face-to-face contact. Interestingly, three studies^{52,70,72} that demonstrated significant changes contained the element of intergenerational engagement between older adult study participants and younger adult students. Gardiner, Geldenhuys, and Gott⁸⁴ looked at elements that should be included in interventions to successfully address social isolation and/or loneliness in the aged population. Three categories were identified: adaptability, productive engagement, and the use of a community development approach. Engagement within a group to socialize and build social connections was part of the productive engagement category. Furthermore, ten Bruggencate, Luijkx, and Sturm²⁶ argued that an intervention is successful in enhancing the social well-being of older adults when targeting their social needs. Interestingly, all of the three facilitators of social participation identified in the present systematic review could be seen as a way to fulfil the social need of social

connections and connectedness.^{26,33} As a consequence, a question arises around whether the technology is an intermediary to fulfil this social need rather than the technology producing the effect.

A major finding from our study was the inconsistent use of terms and concepts related to social participation. Social participation is a multidimensional concept that comprises the dimensions of social connections, volunteering, and engaging with others in activities for personal enjoyment.^{23,85} However, most of the included studies in the present systematic review measured only one specific dimension of social participation: the dimension of social connections. Likewise, other systematic reviews that looked into interventions for social isolation found that a majority of studies mainly assessed outcomes related to this dimension, such as loneliness and social support.^{29,86} While social isolation and loneliness are distinct concepts, they are sometimes used interchangeably by researchers. As social isolation refers to an actual lack of social connections,²¹ the facilitation of social participation can be considered equal to the decrease of social isolation.²⁸ More importantly, an actual improvement and enrichment of social connections does not necessarily mean a decrease in loneliness, defined as the subjective feeling of lacking social connections.²¹ Given these points, the comparability of study findings is limited.

Methodological Quality of Included Studies

Overall, the methodological quality of studies was inconsistent across study designs. It has to be noted that the EPHPP component ratings “blinding” and “confounders” of several studies were difficult to rate due to the lack of a control group. As the EPHPP dictionary did not provide recommendations on how this issue should be addressed, the first author standardized the process by rating these component ratings as weak. In addition, a high selection bias could be observed across quantitative and mixed methods studies because study participants were mainly self-referred. This selection bias might have implications for the findings of the present systematic review. As mentioned before, limited quantitative evidence was found regarding the effectiveness of technological interventions on social participation. An explanation might be that older adults who are contacted and willing to participate in a study are not socially isolated. This explanation can be supported by the included studies that reported a lack of study participants with a high degree of social isolation at baseline.^{50,73-75} In addition, the study participants’ digital literacy, attitudes toward technology, and investment in learning how to use a certain technology may have led to biased study findings. This issue was not covered by the used quality assessment tools. However, some studies addressed this issue by evaluating attitudes toward technology, use of technology, or digital literacy prior to the intervention. Other studies addressed this issue by providing training sessions on how to use the technology or by including study participants based on their digital literacy.

Strengths and Limitations

The strength of this study lies in the systematicity of our approach. The systematic search strategy that combined free text words with Medical Subject Headings (MeSH), Thesaurus terms, and CINAHL Subject Headings ensured the inclusion of relevant studies from various scientific databases. Moreover, the continuous involvement of two independent researchers throughout the entire review process enhanced the rigour of the screening and quality appraisal process. Using three different quality assessment tools enabled a thorough quality appraisal of the included studies, regardless of their design.

A number of potential limitations need to be considered. Firstly, a publication bias might have occurred, as this review was restricted to published results. Furthermore, the search was limited to studies written in English and published in peer-reviewed journals. Hence, research findings published in other sources, such as trade journals, were excluded. As such, potentially relevant publications may have been missed. Nevertheless, measures were taken to ensure the comprehensiveness of our search: the use of citation tracing, the use of different search terms related to the concept of social participation, and the inclusion of database-specific subject headings. Despite this, the search terms used in this systematic review may not cover all relevant studies since researchers use different terms to refer to the multidimensional concept of social participation. Secondly, included studies might be falsely considered as mixed methods studies, even when the respective study authors did not intentionally use a mixed methods design. Consequently, the methodological quality of those studies may have been rated inappropriately. Lastly, this systematic review included studies with diverse research designs and inconsistent methodological quality. The generalizability of the review findings may as a result be limited. However, the diversity of study designs broadened the scope of this review, identifying various technological interventions that target the social participation of community-dwelling older adults.

Implications for Practice and Future Research Directions

The present findings have implications for targeting the growing health issue of social isolation in the aged population. Due to the COVID-19 pandemic, social interaction occurred mainly digitally during the past year. As a consequence, older adults living in the community were not only socially excluded from society but were also digitally excluded from society.^{87,88} Based on the present review findings, technology could play a crucial role in addressing these consequences of COVID-19 in community-dwelling older adults by providing opportunities to maintain social connections and to socially participate in the community. Policy makers should therefore prioritize the need of older adults to socially participate in the community and provide technological services to address this need. To ensure that these services can successfully address social participation, they

should incorporate a social interaction element and provide possibilities to engage in out-of-home activities. Moreover, designers of technological interventions that target social participation might incorporate social interaction elements into the intervention.

As new technological solutions emerge every year and the number of older adults experiencing social isolation grows rapidly, future studies need to be carried out to evaluate the impact of emerging technologies on social participation outcomes. To capture the complex nature of social participation, it would be of value for studies to collect both qualitative and quantitative data. Furthermore, there is a need for a consistent terminology. Researchers should consider identifying and clearly defining the concept of interest in their studies. Due to a lack of an outcome measure that covers diverse social participation dimensions, studies should combine several validated outcome measures to assess social participation. Future studies should consider developing and validating an outcome assessment that covers all dimensions of social participation. Different healthcare professionals, such as occupational therapists, could use the tool to tailor their intervention to the individual needs of older adults living in the community. As the purpose of social participation is to facilitate the involvement in activities in the community,²³ more studies should look into using technology to facilitate participation in out-of-home social activities. In order to evaluate the long-term effects of technological interventions on social participation, studies with larger sample sizes that focus on older adults with a high degree of social isolation are needed. In addition, researchers not only should look into the effects of technological interventions but also should explore whether these effects are mediated rather than produced by the technology.

In this systematic review, a lack of studies that address community-dwelling older adults with dementia was identified. Therefore, an important aspect to explore in future studies is the potential of technological interventions to reduce the social isolation of this study population. Moreover, it is likely that factors other than the ones identified in this review play a role in facilitating the social participation of people with dementia. According to Dröes et al.⁸⁹, personal and disease-related factors, social environment factors, and physical environment factors can impede or enhance their social participation. Similarly, the findings of Gaber et al.⁹⁰ suggest that contextual factors, such as characteristics of the physical and social environment, need to be considered when enhancing the social participation of people living with dementia. Further research should focus on identifying factors of technological interventions that facilitate social participation in older adults and, particularly, in older adults with dementia.

CONCLUSIONS

Technological interventions have shown the potential to alleviate loneliness and social isolation and to enhance social support. In particular, technological interventions that contain the elements of social interaction, face-to-face contact, or social engagement seemed to be most effective. This review is a starting point for future research regarding the use of technology to facilitate social participation among older adults and to thereby reduce their (risk of) social isolation, especially in the context of dementia.

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SUPPLEMENTARY MATERIALS

Appendix 1. Screening tool

Citation and title screening

1. Does the citation indicate publication on or after 2000?
Yes: continue screening
No: stop screening
2. Does the title use English?
Yes: continue screening
No: stop screening
3. Is an abstract available?
Yes: continue screening
No: stop screening

Abstract/full-text study screening

4. Does the abstract/full-text study use English?
Yes: continue screening
No: stop screening
5. Does the abstract/full-text study indicate that the study evaluated an intervention (an intervention is tested and effects are described – doesn't matter if qualitative, quantitative, or mixed-methods design)?
Yes or Unsure: continue screening
No: stop screening
6. Does the abstract/full-text study indicate that the studied intervention used technology?
Yes or Unsure: continue screening
No: stop screening
7. Does the abstract/full-text study indicate that the study population is aged 55 and older?
Yes: continue screening
No: stop screening

8. Does the abstract/full-text study indicate that the study population consist of healthy older adults/older adults in general OR older adults with cognitive impairments or dementia?

Yes: continue screening

Definition cognitive impairments/dementia: people with a diagnosis of Alzheimer's disease, vascular dementia, frontotemporal dementia, Pick's disease, Lewy body dementia, Korsakoff syndrome, Creutzfeldt-Jakob disease, Parkinson's disease dementia, Posterior Cortical Atrophy (PCA), cognitive impairment – such as Mild Cognitive Impairment (MCI) – and non-specified dementia

No: stop screening

9. Does the abstract/full-text study indicate that the older adults were community-dwelling?

Yes or Unsure or not mentioned: continue screening

For example: the study population was living independently in the community, living in the community with friends, family and/or informal caregivers, or living in an assisted living facility/residential aged care.

No: stop screening

For example: The study population was living in a nursing home.

10. Does the abstract/full-text study indicate that the at least one outcome is related to the older adult with or without cognitive impairment or dementia)?

Yes or Unsure: continue screening

No: stop screening

For example: The outcomes are related to the intervention (e.g. the acceptability/usability of the intervention/technology).

11. (a) Does the abstract/full-text study clearly state that the intervention was intended to improve social participation or to reduce social isolation/loneliness of the older adult?

OR

(b) Does the abstract/full-text study indicate that at least one outcome is related to the social participation/social isolation/loneliness of the older adult?

Yes or Unsure or not mentioned: continue screening

We use the definition of social participation by Levasseur et al.²³: a "person's involvement in activities that provide interaction with others in society or the community".^(p.2148)

No: stop screening

Inclusion/Exclusion Decision

- a. Included, all questions were answered “Yes”, “Unsure” or “Not mentioned”
- b. Excluded, at least one question was answered definitely “No”

Appendix 2. Data collection form: Technological interventions to enhance social participation in dementia

Study title	
Study ID <i>(surname of first author and year first full report of study was published e.g. Smith 2010)</i>	
Paper ID <i>(from Excel file)</i>	
Date form completed <i>(dd/mm/yyyy)</i>	
Publication type <i>(e.g. full report, paper, conference paper)</i>	

General Study Characteristics

	Descriptions as stated in report/paper	Location in text or source <i>(pg. & ¶/fig/table/other)</i>
Aim of study <i>(e.g. efficacy, equivalence, pragmatic)</i>		
Design of study <i>(please specify how the authors define the design)</i>		
Country of data collection <i>(please specify location and the social setting)</i>		
Ethical approval obtained for study	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear/not described	
Theoretical concepts related to social participation <i>(e.g. social connectedness, social isolation, loneliness, ... specify the definition used)</i>		

Study population	___ Older adults in general (excluding older adults with cognitive impairments) ___ Older adults in general (including older adults with cognitive impairments) ___ Older adults with cognitive impairments Other, namely _____	
	Participants <i>N:</i> <i>Mean age:</i> <i>Age range:</i> <i>Male:</i> <i>Female:</i>	
	Inclusion/exclusion criteria	
	Withdrawals, exclusions and drop-outs (<i>provide reasons if stated</i>)	

Intervention characteristics

	Description as stated in report/paper	Location in text or source (<i>pg. & ¶/fig/table/other</i>)
Description of the intervention/ technology	Experimental intervention: (N =) Comparison intervention: (N =)	
Aim of intervention		
Duration of intervention period		
Timing (<i>e.g. frequency, duration of each episode</i>)		
Providers (<i>e.g. research assistant, health care professional, researcher</i>)		
Setting		
Theoretical basis of the intervention		

Outcomes

Copy and paste table for each outcome

	Description as stated in report/paper	Location in text or source (pg. & ¶/fig/table/other)
Outcome name (just for quantitative/mixed methods studies)		
Outcome definition (just for quantitative/mixed methods studies)		
Time points measured (specify whether from start or end of intervention)		
Outcome measures (please tick and specify the data collection methods)	<input type="checkbox"/> QUANTITATIVE <input type="checkbox"/> QUALITATIVE <input type="checkbox"/> MIXED METHODS	
Scales: upper and lower limits (indicate whether high or low score is good, just for quantitative/mixed methods studies)		
Is outcome/tool validated? (just for quantitative/mixed methods studies)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/> Not applicable	

Findings and influencing factors

	Description as stated in report/paper	Location in text or source (pg. & ¶/fig/table/other)
Main findings of the study		
Factors explaining the success or failure of the intervention in influencing social participation		

Other information

Key conclusions of study authors	
Correspondence for further study information	
Notes:	



CHAPTER 5

Geographic Information System (GIS) based intervention 'Viamigo' to support independent out-of-home mobility from a distance: A single-arm feasibility trial in people with dementia and their informal caregivers

Pascale Heins, Lizzy M.M. Boots, An Neven, Jessie C.M. Bongaerts, Frans R.J. Verhey, &
Marjolein E. de Vugt

In preparation



The background of the page is a solid dark blue. Scattered across this background are several stylized, golden-yellow dandelion seeds with their feathery parachutes. The seeds are positioned at various heights and angles, some appearing to be in motion as if blowing in the wind. They are primarily located on the left side and bottom of the page, framing the central text.

CHAPTER 6

Bridging gaps in the design and implementation of socially assistive technologies for dementia care: The role of occupational therapy

Wei Qi Koh, Pascale Heins, Aisling Flynn, Aysan Mahmoudi Asl, Lesley Garcia, Camilla Malinowsky, & Anna Brorsson

Disability and Rehabilitation: Assistive Technology, 2022

ABSTRACT

Dementia is a global health challenge, and people living with dementia (PLWD) are especially susceptible to reduced engagement in meaningful occupations, including social participation. In the past few decades, socially assistive technologies continue to be developed amidst a rapidly evolving technological landscape to support the social health of PLWD and their caregivers. Examples include social robots, virtual reality, smart home technology, and various digital technologies, such as mobile applications for tablets and smartphones. Despite an increasing body of research and interest in this field, several gaps relating to the design and implementation process of socially assistive technologies continue to undermine their relevance for PLWD in daily life. In this paper, some of these gaps are highlighted and the role of occupational therapy in the design and implementation of socially assistive technology is presented. In the design process, occupational therapists are uniquely skilled to advise and advocate for the tailoring and personalisation of technology to address the occupational needs of PLWD. In the implementation of socially assistive technologies, occupational therapists are skilled to educate, train, and conduct ongoing evaluations with PLWD and their caregivers, to incorporate socially assistive technologies into their routine and daily lives. We recommend that occupational therapists should continue to be acquainted with such technologies through continuous professional development and educational curricula. Moreover, we highlight the necessary collaboration between occupational therapists, technology developers, and researchers to enhance the process of designing and implementing socially assistive technology, so that their relevance for PLWD and their caregivers can be maximised.

Implications for rehabilitation

- Developers and designers of socially assistive technology should consider the disease trajectory of different types of dementia, as well as the different needs, abilities, preferences, occupations and routines of people living with dementia (PLWD) and/or their caregivers.
- Collaborations between technology developers, researchers, and occupational therapists should take place iteratively throughout the process of designing and implementing socially assistive technology to maximise their relevance and applicability for people living with dementia and their caregivers.
- To continue enhancing the current role of occupational therapy in socially assistive technology provision, occupational therapists should keep up to date with socially assistive technology that are being developed to support the social health of PLWD.

INTRODUCTION

Dementia is expected to affect 152 million people worldwide by 2050 and has been highlighted as a global health priority by the World Health Organisation.¹ It is characterised by a decline in one or more cognitive domains, which include complex attention, executive functioning, learning, memory, language, perceptual skills, and social cognition.² While there are different types of dementia, most are progressive in nature. During the prodromal stage, people living with dementia (PLWD) may continue to live independently with or without support.³ Cognitive and functional decline, as well as behavioural changes, often become more apparent through the moderate and advanced stages of dementia.⁴ Such decline may limit their ability to engage in meaningful occupations, which are defined as the things that people need to, want to, and are expected to do in their everyday lives.⁵ PLWD often experience reduced meaningful social engagement, leading to loneliness and social isolation as the disease progresses.⁶ However, being engaged in personally meaningful social activities, such as meeting friends and family, is an important determinant of successful adaptation and ageing whilst living with a chronic disease,^{7,8} including dementia. Furthermore, successful engagement in meaningful social activities can result in reduced responsive behaviours such as agitation, shadowing, and repetitive questioning^{9,10}; provide a feeling of connectedness with self, others, and the environment; and promote life satisfaction and quality of life for PLWD^{6,8}.

Technology plays a relevant role in supporting individuals to live well with dementia.¹¹ Over the last few decades, there has been a growing body of research that focussed on developing and evaluating assistive technology (AT) for PLWD.¹²⁻¹⁴ The COVID-19 pandemic has further accelerated the research on and the use of AT, which has been paramount in enhancing the social health of PLWD during periods of social distancing restrictions.^{15,16} Assistive technology may be defined as “any item that enables a person with a disability to complete a task that they would otherwise be unable to do”.^{17(p.525)} AT can range from everyday technology such as alarm clocks and telephones, to information and communication technology.¹⁸ However, we will focus specifically on socially assistive technology. In this paper, we define socially assistive technology as AT that is specifically designed for and/or used to promote social health among PLWD by enhancing their capacities to 1) fulfil their potential and obligations, 2) manage life with some degree of independence, and 3) participate in social activities.^{7,19}

Recent evidence shows that different types of socially assistive technology have been used to enhance the social health of PLWD.²⁰⁻²² Everyday technology, such as mobile phones, has been increasingly leveraged as digital medium for a myriad of applications to benefit the social health of PLWD.^{20,21,23} Common examples include Skype and Zoom, which have been used to enhance social connections.^{24,25} With continued digitalisation,

robotics, virtual reality (VR) and smart home technology also have emerged as novel technologies to support PLWD to engage in different social activities.^{26,27} Despite the growing interest in this field, a recent scoping review has highlighted several factors which hindered the application and adoption of socially assistive technology in daily life.²⁷ Pertinent issues relate to their design and implementation processes, which can limit their relevance for PLWD and uptake in their daily life. Furthermore, the use of socially assistive technology for PLWD can be a double-edged sword. While it is intended to enhance social connections and productivity, it can also simultaneously isolate or alienate the intended users¹¹ if used improperly, or designed without considering the (current and changing) functional capacities and needs of PLWD and their caregivers. Therefore, it is important to reflect on the gaps in the design and implementation of socially assistive technologies and suggest considerations for practice that will enhance their adoption.

Occupational therapy

Occupational therapy is a healthcare profession that is uniquely positioned to promote engagement in meaningful occupations, and to enhance the social health of PLWD through 1) supporting the maintenance and remediation of their skills and abilities; and 2) modifying their activities or environment.²⁸ Occupational therapy is the leading healthcare profession in the prescription and provision of AT, as evidenced by findings of an international survey that involved participants from 52 countries.²⁹ Occupational therapists work with a wide range of population, including children³⁰ and adults with disabilities,³¹ older adults,³² and individuals with chronic health conditions such as dementia.³³ One of the key roles of occupational therapists entails assessing, prescribing, educating, and training individuals and their family members to use AT in their daily lives.³³⁻³⁵ This has played an important role in equipping users with the relevant skills and confidence to use AT and reducing the likelihood of technology abandonment.³⁶ For instance, in Ireland, occupational therapists lead Memory Technology Resource Rooms to educate, support and prescribe AT for PLWD and their care partners. Similar services are available in other countries, such as the UK³⁷ and Australia³⁸.

The current role of occupational therapy lies mostly in the provision of AT that aims to enhance physical or cognitive health.²⁹ As such, it is a logical extension for occupational therapists to familiarise with and be more involved in AT to enhance social health, a (relatively) newer field of technology development. This will position occupational therapists in a better stead to introduce such technology to PLWD. In similar regard, information about the knowledge and expertise of occupational therapists should be actively disseminated to technology developers and researchers, to raise awareness of the role of occupational therapy in the design and implementation of socially assistive technology, and to advocate for the inclusion of occupational therapists in these processes.

The primary objective of this paper is to propose practicable considerations for bridging pertinent gaps relating to the design and implementation of socially assistive technology for PLWD and their caregivers from an occupational therapy lens, and to highlight the necessary collaboration between occupational therapists, technology developers and researchers. Firstly, a brief overview of socially assistive technology will be presented. These examples include social robots, digital technologies, virtual reality, and smart home technology. Each technology will be described, along with the current state of evidence on their impacts on social health. Next, current gaps and limitations to their design and implementation will be highlighted. Finally, practical considerations for addressing these gaps will be proposed, based on literature supplemented with the authors' clinical and professional expertise. The authors comprise a panel of experienced and internationally diverse occupational therapy clinicians, researchers, and educators from the 1) Dementia: Intersectoral Strategy for Training and Innovation Network for Current Technology (DISTINCT) consortium, which focuses on conducting research on using technology to support the social health of PLWD; 2) the Science Foundation Ireland (SFI) Centre for Research Training in Digitally Enhanced Reality (D-Real), which focuses on research involving the use of digital technology; and 3) the Division of Occupational Therapy at Karolinska Institutet, Sweden.

SOCIALLY ASSISTIVE TECHNOLOGIES AND THEIR IMPACTS

Social robots

Social robots are developed to facilitate and maintain social networks between people, reduce social isolation, and provide an array of services for PLWD, such as cognitive training and affective therapy.³⁹ Social robots may be categorised as socially assistive, telepresence, or pet robots based on their functions.²⁷ Socially assistive robots have several functions alongside their function to enhance social networks, such as providing medication reminders. Examples of such robots include Nao and Pepper, which have been used across different dementia care settings.^{40,41} Next, telepresence robots incorporate a video conferencing platform to facilitate and maintain social interaction. Examples of telepresence robots include Giraff and Double, which have been used in countries such as Australia and Finland.^{42,43} Finally, pet robots are designed to resemble and behave like pets. They are intended as substitutes for live animals to provide physiological and emotional benefits for people with dementia.⁴⁴ Examples include PARO (seal), JustoCat (cat), AIBO (dog robot), and Pleo (dinosaur). Several studies have been conducted to investigate the impact of the aforementioned social robots on PLWD. Synthesised

findings suggest that social robots had positive impacts on the psychosocial domains of older adults - including PLWD - such as reducing loneliness and enhancing social engagement interaction.⁴⁴⁻⁴⁶

Digital technology and virtual reality

Several phone- and tablet-based interventions continue to be developed, refined, and/or evaluated for PLWD and their caregivers to promote their social health.^{20,21} Some examples include Photoscope, a digital person-centred artistic photo-activity to enhance the social interaction between PLWD in long-term care facilities and their informal caregivers,⁴⁷ and I-CARE, a tablet-based system to enhance the dyadic relationships between community-dwelling PLWD and their informal caregivers⁴⁸. Other examples of digital technology interventions that leverage more established technology platforms include digital gaming technologies, such as exergames⁴⁹ or games using iPads, Nintendo Wii, and Nintendo DS.¹⁵ Findings from recent systematic reviews suggest that such digital technologies show promise in enhancing social participation and social support, and reducing social isolation and loneliness among PLWD.^{20,21} They also show potential in enhancing social interaction between PLWD and their (informal) caregivers^{15,47-49} and support engagement in meaningful social activities^{48,50}.

Virtual reality (VR) is a novel technology involving a “computer-simulated real or imagined environment that enables users to experience the sensation of being present in a different physical place”.^{51(p.558)} VR provides a unique, novel, and safe virtual world for PLWD to participate in meaningful or reminiscent activities including social activities⁵² that may be difficult for PLWD and their caregivers in daily life, due to physical or logistical difficulties. VR may be conducted individually or in a group-based setting to increase opportunities for social interaction, socialisation, and social engagement.^{53,54} A qualitative evidence synthesis on PLWD’s experiences and perceptions of using VR revealed that it can provide a means of unlocking the PLWD’s connections with formal, informal caregivers and peers.²⁶ Sociability outcomes were reported when using VR with others and resulted in sustained sociability where the PLWD reflected on the experience and anticipated subsequent use with peers.²⁶

Smart home technology

Smart home technology broadly refers to the connection and automation of appliances and devices within a home environment via the internet. This connectivity of devices via the internet - known as the Internet of Things⁵⁵ - uses sensors to monitor and effect change to enhance individuals’ experiences of living at home. In the context of dementia, smart home technology has been designed and used to monitor, support and maximise

independent living abilities, and to support social connections.⁵⁶⁻⁵⁸ Some examples include Amazon Echo and Alexa which are available off-the-shelf, the Rosetta,⁵⁹ and Dem@Care systems,⁶⁰ which are more recently developed (or being developed) for PLWD and their caregivers. A recent review showed that while only a handful of studies have been conducted to evaluate their effectiveness on PLWD,⁶¹ there is some evidence of positive impact on performance in activities of daily living, amongst other health outcomes such as depression and anxiety.

EXISTING KNOWLEDGE GAPS AND CONSIDERATIONS FOR PRACTICE

“To be leaders, we (occupational therapists) can bring our expertise and understanding of meaningful human occupation into the discourse, design, and implementation of technologies.”^{62(p.281)}

Designing socially assistive technology

Despite their potential, there are several gaps and challenges to the design of these socially assistive technologies. A recent scoping review outlined several barriers related to the design features of such technologies for older adults and PLWD such as complex user interfaces and unclear or unpredictable actions.²⁷ Technology developers play a crucial role in designing technologies for PLWD. However, due to a different disciplinary focus, they do not often have experience working with PLWD and use other models than social and humanistic models and frameworks to guide their design process.³³ This could lead to the omission of design features that are integral for supporting PLWD and their caregivers.⁶³ For instance, in a pilot study by Barrett and colleagues⁶⁴, PLWD experienced difficulties using a socially assistive robot, as the user interface required PLWD to raise their arms to access the touchscreen from a seated position. This physical movement proved to be physically challenging, as the older population often experiences frailty.⁶⁵ In turn, caregivers had to provide support to overcome such challenges.⁶⁴ Given that a key driver behind the development of such technologies is to alleviate care provision, it is ironic that caregivers have to provide additional support to PLWD to account for such design limitations. Moreover, the functions of socially assistive technologies do not always align with the occupational needs of PLWD.^{26,27,66,67} For instance, in a study by Orejana et al⁶⁸, users were provided with a socially assistive robot to support them in different aspects of daily life, such as providing medication reminders and providing entertainment. However, some of these features were not relevant as the users were

still capable of self-management. This highlights that personalising and tailoring the functions of socially assistive technologies to the individual abilities, needs, and fluctuating emotions of PLWD, remains a pertinent technology development gap.⁶⁹

While strides have been made to include healthcare professionals, such as nurses and medical staff, in the development and research on technology, technology developers appear to be unaware of the role, expertise, and impact of occupational therapists in assistive technology provision for PLWD.⁷⁰ Although other healthcare disciplines have parallels in terms of their positionality and philosophy of care, the occupational therapy profession can offer a unique, occupation-focussed perspective. Occupational therapists work closely with PLWD and their caregivers to assess and design interventions, including AT prescription, to support their participation in meaningful (and social) occupations. Assessments are often guided by occupational therapy conceptual models, which serve as frame of references to gain a holistic understanding about an individual.⁷¹ For instance, the Person-Environment-Occupation (PEO) model guides comprehensive considerations about the person with dementia (e.g., personal values, physical, cognitive, and social abilities), their environment (e.g., their physical, institutional and social environments, such the extent of support from caregivers), their occupations (e.g., daily routines), and how each may evolve over the life trajectory.⁷² Another example is the Human Activity Assistive Technology (HAAT) model that is often used to guide assessments of the dynamic interactions considering the person, the activity (i.e., occupations), the context (i.e., environment) and the assistive technology (i.e., environment).⁷³

While important, an occupation-focussed perspective is not always taken into account when designing socially assistive technology for PLWD. As dementia progresses, the types of occupations that an individual and their caregivers engage in often change due to diminishing abilities.⁷⁴ However, there has been insufficient consideration about this aspect of dementia during the design process, which has led to technology abandonment by PLWD and their caregivers.⁷⁵ By the same note, while a familiar and predictable life routine has a profound influence on the function of PLWD,⁷⁶ considerations about how the technology can be designed to align with the daily routines of PLWD and their caregivers are often precluded from the design process.⁷⁷ Rather, they are expected to “fit” the AT in their lives.¹³ The findings from an ethnographic study describing the use of smart home technology with PLWD and their caregivers exemplify the abovementioned points.⁷⁸ In the study, an individual with dementia had to don a wearable device which was unfamiliar to her and her routine, which led to infrequent use. Using the technology also required the individual to activate a device, a task that warrants several cognitive functions such as attention and working memory – which decline as part of the disease trajectory. In turn, her caregiver had to request an alternative wearable device, and “remind” her to use it. These omissions highlight the importance of integrating occupational therapy expertise to address pertinent gaps in the design of socially assistive technologies. Activity analysis

is a core occupational therapy skillset involving thorough analysis of the demands of an activity and identifying the necessary skills for activity engagement.⁷⁹ In the context of socially assistive technologies, activity analysis may address important design features, such as user interfaces, that cater to the abilities and daily needs of PLWD.

Implementing socially assistive technology

Implementing a technology refers to putting it to use in practice in daily lives. Even though technology may prove to be effective for people with dementia in a research study, successful implementation in daily life goes beyond research evidence that demonstrates their effectiveness.²⁷ Similar to the gaps highlighted in the technology design process, the mismatch between the socially assistive technology and the dynamic needs (i.e., existing and changing needs) of PLWD and their caregivers have challenged their uptake. Previous studies⁸⁰⁻⁸² have highlighted this as an important predictor of AT abandonment. Insufficient facilitation, knowledge, and training to support PLWD and their caregivers to integrate AT into their daily routines have also challenged implementation efforts.¹² For instance, Gibson et al.¹⁸ found that family members were unclear about when technology should be introduced to PLWD. In another study, Chang and colleagues⁸³ found that users had poor engagement with a social robot in a group setting without facilitation by a therapist.

Deliberate efforts must be made to bridge these gaps to enhance their implementation. Like the role of occupational therapy in the provision of other ATs, occupational therapists should be consulted to identify and match the “right” socially assistive technology to the “right” individuals (i.e., PLWD and/or their caregivers). This will involve discussions to identify activities that are meaningful to PLWD and/or their caregivers, assessing the functional capacities of PLWD, and assess the ability of the AT to address their dynamic social needs and wants.^{9,10,84-86} These considerations may inform the prescription of socially assistive technology and supporting interventions, to empower PLWD and their caregivers to engage meaningfully with the technology. In consideration of the progressive nature of dementia, it is also necessary to factor in regular reassessments of the needs and abilities of PLWD and their caregivers.⁸⁷ While these constitute key elements of current occupational therapy practice – given a rapidly evolving technological landscape – occupational therapists should actively acquaint themselves with evolving and emerging socially assistive technology to ensure that they are well-informed to advise on suitable and desirable AT for PLWD and their caregivers.

Thereafter, formal and/or informal caregivers should be coached to support PLWD through problem-solving, identifying, and simplifying steps required to use and embed the socially assistive technology in their daily lives.^{88,89} These are important strategies to enhance PLWD’s abilities to participate in activities.⁸⁸ Such interventions may encompass

the use of strengths-based approaches,⁹⁰ caregiver training, activity gradation and modifications,⁸⁸ and other cognitive strategies such as a combination of errorless learning and spaced retrieval^{91,92}.

When implementing socially assistive technology in a group-based setting, for example in a day-care or residential setting, it is also necessary to carefully consider group dynamics, such as the attributes of PLWD who are participating, group size, and the similarities or differences in their values or abilities.⁹³ Correspondingly, skilled facilitation is necessary to enhance group processes,^{93,94} to ensure that PLWD can engage meaningfully with the socially assistive technology in the group setting. In one study, group facilitation techniques supported older adults' engagement with a social robot.⁸³ These group facilitation techniques included carefully tailoring the social and physical environment to the older adults' abilities. Occupational therapy clinicians and trained occupational therapy assistants can contribute to this gap by tailoring and facilitating group-based use of socially assistive technology, or by training other healthcare professionals to facilitate group-based use of socially assistive technology.

DISCUSSION

We provided an overview of socially assistive technologies that have been (and are being) developed to benefit the social health of PLWD, such as social robots, digital technologies, virtual reality, and smart home technology. Although more controlled studies with larger sample sizes and more rigorous designs are needed, several studies^{20,21,26} highlight their promise. We also identified several gaps in their design and implementation and discussed ways in which the unique skills of occupational therapists, and their focus on PLWD and their caregivers' daily lives and occupational engagement, could be used to bridge these gaps.

Given that engagement with AT by PLWD is potentially a transformative, health-promoting occupation in itself, as well as the means by which PLWD may influence their own health, it is incumbent on the profession of occupational therapy to contribute its theoretical and practice expertise to this emerging aspect of health and social care. Occupational therapy "enablement skills" of adapting, advocating, coaching, collaborating, consulting, coordinating, designing/building, educating, engaging, and specialising would all be called upon in various ways at various stages along the design to implementation pathway.⁹⁵ At the design phase, collaboration and consultation with interdisciplinary teams, including occupational therapists, can improve the design of adaptive interfaces and functionality to meet the (changing) needs of PLWD and their caregivers. This approach could further support the development of participatory and co-design methodologies. At the implementation phase, occupational therapists' skills

in educating and coaching users, designing and coordinating programmes, consulting with health systems, and advocating at the policy level could improve the adoption, engagement, and spread of socially assistive technologies in the everyday life of PLWD and their caregivers.⁹⁶ Examples of such initiatives may include the development of targeted educational and training materials that are tailored to PLWD and their caregivers, care providers, and health systems.

Despite the rapid technological advancements in socially assistive technology intended to enhance the social health of PLWD and their caregivers, such technologies have ironically not become a part of mainstream dementia care. They have not been widely adopted by healthcare professionals, including occupational therapists. Despite having a well-established role in traditional AT provision, occupational therapists seem to be less informed of socially assistive technologies that continue to be developed, and their potential to influence the social health of PWLD.^{33,69} Therefore, alongside efforts that should be made to involve occupational therapists in the design and implementation of socially assistive technology, efforts should also be made to move socially assistive technology into clinical practice and the education curriculum for the next generation of healthcare professionals, including occupational therapy clinicians.

Subsequently, strategies at the education and post-qualification level should be developed to sustain this movement. Including contextualised learning in education curricula for healthcare professionals, such as the use of simulation, could be one strategy to ensure readiness for using socially assistive technologies in practice.⁹⁷

We also echo calls from the Human-Computer Interaction (HCI) research community to embrace interdisciplinarity for the benefit of end-users. Occupational therapists, like HCI researchers and other healthcare professionals, share an obligation to aim for the highest ethical standards in research and practice. These collaborative actions we propose here could have far-reaching implications in terms of improving digital equity and occupational justice; PLWD should have the rights and opportunities to leverage on socially assistive technology to support their engagement in meaningful occupations.⁹⁸ Therefore, we encourage both occupational therapy and HCI practitioners to reach out to each other to avoid this blind spot and to work together collaboratively in this mutual endeavour. Occupational therapists specialising in roles as dementia researchers themselves could be most effective in bridging the gap between the two communities of HCI researchers and behavioural scientists with an occupational therapy background. Furthermore, we recognise the need to include people with dementia and their caregivers in the development of technology for PLWD and related research as experts by experience. In recent studies, people with dementia expressed the wish to participate in research regarding interventions and technologies addressing their social health.^{69,99} Moreover, involving PLWD in the development of supportive technology has been shown to facilitate the personalisation of functions to end-users.^{100,101}

RECOMMENDATIONS

We have highlighted several gaps in the current design and implementation of socially assistive technologies for PLWD and have suggested considerations for practice based on our expertise as occupational therapists and researchers in the field of using technology to improve the social health of PLWD supported by the literature. A summary of the considerations that are relevant for technology developers, HCI practitioners, occupational therapists, and other professions included in the design and implementation of socially assistive technologies for PLWD, can be found in Table 1. These occupations-based considerations are important steps that could bridge pertinent gaps in existing design and implementation processes and maximise the relevance of socially assistive technology for PLWD and their caregivers.

Table 1. Recommendations to enhance the design and implementation of socially assistive technologies.

A) Designing socially assistive technology	
<i>Gaps</i>	<i>Considerations for bridging the gaps</i>
<p>1. Not considering (and anticipating) the current and evolving needs, preferences, abilities, and occupational preferences of PLWD and their caregivers</p> <p>Dementia is progressive; this means that the abilities of PLWD to engage in their day-to-day routines can change over time. Correspondingly, their needs and ability of PLWD and their caregivers to interact with and use the technology can also evolve rapidly.</p>	<ul style="list-style-type: none"> • Technology developers and occupational therapists (researchers, educators, and/or clinicians) could reach out to each other to collaborate in the (iterative) process of designing technology. The outreach may be done through clinical services or national representative organisations for the occupational therapy profession. • Technology developers and researchers could consider the disease trajectory of different dementias and understand the implications on the functional abilities and needs of PLWD and their caregivers. • Technology developers and researchers could consult with occupational therapists who have knowledge of holistic and occupation-based models to enhance the comprehensiveness of considerations for technology design in relation to PLWD and their occupations. Examples include the Person-Environment-Occupation (PEO) model and the Human Activity Assistive Technology (HAAT) model. • Occupational therapists could engage in professional development and further education to keep up to date with emerging technology and advocate for active occupational therapy involvement. • Educators could consider educating about socially assistive technology within the occupational therapy educational and professional development curriculum.
<p>2. Not aligning the function of socially assistive technology with the occupational needs of PLWD and their caregivers</p> <p>Each individual and their caregiver may have different needs and preferences. Therefore, a tailored approach to technology development is needed.</p>	
<p>3. Not aligning socially assistive technology with the daily (and familiar) routines of PLWD and their caregivers</p> <p>Familiar routines are important for PLWD (and their caregivers), as such considerations about how technology can be designed to align with the routine of PLWD and their caregivers have to be made explicit.</p>	

Table 1. Continued.

B) Implementing socially assistive technology	
<i>Gaps</i>	<i>Considerations for bridging the gaps</i>
<p>1. Not facilitating PLWD and their caregivers to choose the “right” socially assistive technology Different socially assistive technology may suit different PLWD and their caregivers, depending on their unique preferences and needs. For example, a socially assistive technology with medication reminder functions may not as relevant or appropriate for PLWD in residential facilities, or for caregivers who are keen to support PLWD in medications without technology.</p> <p>2. Not facilitating and training to support PLWD and their caregivers to integrate socially assistive technology into their daily routines Routines are important for PLWD. There is an insufficient focus on how the technology can be integrated into the daily lives of PLWD and their caregivers.</p> <p>3. Not facilitating the use of socially assistive technology in dementia care facilities In dementia care facilities, the use of technology may occur in a group setting.</p>	<ul style="list-style-type: none"> • Technology developers and researchers could consider establishing a relationship with national assistive technology clinics and services to inform clinicians about emerging technologies, to support the uptake of these technologies by PLWD and their caregivers. • Occupational therapists could consider: <ul style="list-style-type: none"> (i) collaborating with technology developers and researchers to design comprehensive assessments to match and to tailor the socially assistive technology to PLWD and their caregivers, and (ii) developing a clear intervention plan to train and equip them with the skills and confidence to use the technology in their daily lives. • Occupational therapists and service providers (e.g., assistive technology clinics and providers) could factor in regular re-assessments of the changing needs and diminishing abilities of PLWD and their caregivers to determine the suitability of the socially assistive technology over time. • Service providers (e.g., healthcare providers, dementia care facilities) could work with occupational therapists to design and facilitate the use of socially assistive technology in shared/ group-based settings. An example includes group-facilitation techniques.

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CHAPTER 7

General discussion

INTRODUCTION

Social participation is associated with improved health,¹ quality of life² and life satisfaction³ in people with dementia. For those living with dementia, it is a crucial element of living well.^{4,5} However, people with dementia can experience a decline in social participation.^{6,7} Therefore, a growing body of literature explores the experience of social participation in dementia, including influencing factors and interventions.⁶⁻⁹

Technological interventions are promising in fostering social participation among older adults living in the community.^{10,11} However, literature is scarce on the potential of technology in promoting the social participation of people living with dementia.¹² This indicates a need to get a better understanding of social participation in dementia, including the potential added value of technology in promoting social participation of people with dementia living in the community.

Therefore, this thesis aimed to get an understanding of experiences of social participation in dementia (Part 1), including factors shaping this experience, and the role technology can play therein (Part 2).

SUMMARY OF MAIN FINDINGS

This thesis embarked on a comprehensive exploration of social participation in people with dementia, encompassing their concerns, experiences, and the potential role of technology therein.

Part I gained insight into the social participation experiences of people with dementia and related concerns. **Chapters 2 and 3** shed light on their awareness of the challenges and risks involved in engaging in social activities outside their homes, as well as their increased reliance on their social environment. Although the number of places visited for social participation did not significantly correlate with personal concerns, participants with dementia demonstrated heightened alertness when participating in social activities, as highlighted in **Chapter 2**. This heightened alertness encompassed their increased attention to finding their way, preventing falls, and keeping track of their valuables. A qualitative exploration of the lived experience of people with dementia (**Chapter 3**) revealed that an increased dependence on the social environment facilitated their continued participation in social activities outside the home. Moreover, participants with dementia actively chose physical and social environments that supported the continuation of social participation, such as places that provided a sense of comfort and safety or social interactions that strengthened their sense of identity and belonging. Furthermore, findings revealed that spouses of participants with dementia faced a significant challenge in maintaining a balance between providing support and respecting their personal boundaries.

Part II explored the potential impact of technology on the social participation of people with dementia. **Chapter 4**, a systematic review, indicated that technological interventions had small but limited effects on alleviating loneliness, reducing social isolation, and enhancing social support. Nonetheless, it is noteworthy that included studies mostly focused on older adults without cognitive impairments, suggesting a research gap in the potential added value of using technology to promote social participation among people with dementia. **Chapter 5** delved into the feasibility of a Geographic Information System (GIS)-based intervention (*Viamigo*) for individuals with dementia and their informal caregivers. The findings revealed challenges related to participant recruitment and *Viamigo*'s usability, emphasizing the importance of co-creation in development processes to enhance the acceptability and feasibility of technological interventions. Finally, **Chapter 6** underscored the valuable role that occupational therapists could play in these development processes, as well as implementation processes. Occupational therapists have unique skills, enabling them to tailor and personalize technology to address the occupational needs of individuals with dementia. Additionally, they excel in evaluating and facilitating the integration of technology into daily routines. Given these unique skills, the chapter set out recommendations for practice, highlighting the

need for collaboration among all relevant stakeholders involved in the development and implementation process. This collaboration should ideally include occupational therapists, researchers, technology developers, and people with dementia.

Taken together, these findings underscore the complexity of social participation and technology use in individuals with dementia. Furthermore, they highlight the agency and capacity of people with dementia to successfully adapt to changes in their social participation. While technology offers the potential to support this adaptation process, it is essential to address usability concerns and consider co-creation principles in intervention development. Ensuring the inclusion of the expertise of all relevant stakeholders, including occupational therapists, will be essential in unlocking technology's full potential to facilitate the social participation of individuals with dementia.

UNDERSTANDING OF SOCIAL PARTICIPATION IN DEMENTIA

Our findings contribute to the scientific understanding of social participation in individuals with dementia. They challenge the notion of the 'shrinking world',¹³ which suggests that reduced out-of-home activities and fewer visits to places outside the home result in a loss of independence and control. In contrast, our findings highlight the capacity of people with dementia to adapt to the challenges posed by dementia and to make choices that foster social participation, thereby gaining a sense of autonomy and control (**Chapters 2 and 3**). These findings align with recent studies adopting a capability-based approach¹⁴⁻¹⁶ and the concept of social health.^{8,9,17} Our findings additionally indicate that adapting to challenges and risks demands heightened alertness (**Chapter 2**). This heightened alertness can make out-of-home social participation a demanding endeavour for people with dementia.^{18,19}

These findings underscore the complexity of social participation experiences, with the capacity for adaptation varying among individuals. The Adaptation-Coping Model^{20,21} acknowledges that dementia brings a lot of changes that necessitate adjustments by both the person with dementia and their social environment. How individuals and their social environment adapt to these changes depends on their cognitive appraisal of them, influenced by different aspects, such as personal and family history, the individual dementia symptoms and available resources. While some people may automatically adapt to these changes, others may need to develop new coping strategies.²² Consequently, factors, such as the stage and type of dementia, cognitive functioning, and support networks, play a significant role in determining an individual's

ability to adapt successfully. Recognizing these differences can inform more tailored interventions and support strategies.

One strategy observed in **Chapters 2 and 3** involves that people with dementia increasingly rely on their social environment, particularly for out-of-home mobility. This aligns with previous studies that suggest accepting support from others can facilitate social participation outside the home,^{15,23} although it may also lead to feelings of dependency.²⁴ While a lack of independence has often been associated with diminished self-worth in existing literature,²⁵ our findings indicate that, by accepting support, people with dementia can achieve higher levels of independence in social participation. This is in line with the concept of interdependence in dementia.²⁶ Shifting the emphasis from independence to interdependence provides a more inclusive approach to promoting social participation among people with dementia. However, this shift also raises an ethical dilemma of striking a balance between providing support and avoiding overprotection, as caregivers might take over choices to protect their loved ones with dementia.^{24,27,28} Therefore, ethical frameworks, such as shared decision-making and person-centred care, should guide decision-making processes in promoting social participation to empower people with dementia to fully express their choices and preferences.^{29,30}

The exploration of social participation in dementia within this thesis was informed by an occupational perspective, acknowledging that social participation is not only influenced by individual changes but also by contextual factors.³¹ Our findings in **Chapter 3** reveal that people with dementia increasingly seek out familiar places or people who make them feel understood and human during social participation. Looking at these findings from the perspective of the Person-Environment-Occupation model, people with dementia choose environments that support their changed capabilities, needs and values, thereby supporting the continuation of social participation and optimising occupational performance.³² These findings also highlight the importance of engaging in meaningful occupations for people with dementia in the context of social participation. It is important to note that the concept of 'meaning' is highly individualized, varying significantly from one person with dementia according to one's preferences, abilities, and personally relevant goals.³³ Occupational therapists could play an important role in promoting social participation by supporting individuals with dementia in identifying and facilitating occupations that align with their personal values, interests, and goals (**Chapter 6**).

Measuring social participation in dementia

Previous research found that social participation is one of the outcomes that people with dementia find meaningful to be evaluated in psychosocial interventions,^{34,35} highlighting a need for psychosocial intervention trials to include this outcome. However, our systematic review revealed that studies evaluating the effects of technological intervention on the social participation of older adults, both with and without dementia, lack consistency in their approaches to operationalizing and measuring social participation (**Chapter 4**). This lack of consistency has implications for the comparability of effectiveness studies of psychosocial interventions. Additionally, Mangiaracina et al.³⁶ emphasised the need for validated outcome measures for social participation outcome measures in people with dementia, noting that only three instruments were identified, with little information on their psychometric properties, feasibility, and responsiveness.

Reilly et al.³⁷ developed a core outcome set based on input from relevant stakeholders, including people with dementia, researchers, care partners, policy makers and relevant healthcare professionals, to guide the evaluation of non-pharmacological health and social care interventions in dementia research. The core outcome set comprises 13 outcome items, many of which relate to the concept of social health, such as independence, self-management, and the importance of relationships and meaningful activities.³⁷ However, existing outcome measures in dementia research do not adequately reflect what the stakeholders value. According to Harding et al.³⁸, the Engagement and Independence in Dementia Questionnaire (EID-Q) is the most suitable outcome measure to capture the 13 outcome items. In **Chapter 5**, we used the EID-Q to assess the social participation of people with dementia before and after the use of *Viamigo*. Our findings revealed difficulties in administering the EID-Q to people with dementia, as some participants faced challenges with answering the items and showed a decreased concentration towards the end of the 26-item questionnaire. This finding underscores the need for further research into the psychometric properties and feasibility of existing instruments.

Consequently, the question arises of how social participation can be effectively measured in psychosocial interventions among people with dementia to enable cross-study comparisons of intervention effectiveness. Drawing from our findings (**Chapters 2 and 3**), we recommend that outcome measures should focus on the level of adaptation to changes in social participation and overall satisfaction, aligning with the concept of social health.^{8,17} This suggests a shift towards a more individual way to measure psychosocial outcomes,³⁹ taking into account the contextual factors that facilitate or hinder the continuation of social participation (**Chapter 3**). Therefore, we recommend combining both qualitative and quantitative approaches to measure social participation on an individual level, possibly through self-reported goal attainment. However, it is worth noting that goal attainment scales may be less suitable for people in more advanced stages of dementia.⁴⁰

POTENTIAL ADDED VALUE OF TECHNOLOGY

Our findings contribute to our understanding of the potential role that technology can play in the promotion of social participation among older adults, both with and without dementia. Despite the rapid advancements in technology, the exploration of technology's potential to improve social participation among people with dementia has remained relatively understudied (**Chapter 4**). While our systematic review indicated that technological interventions can reduce social isolation among older adults, it revealed a lack of evidence supporting their effects on people with dementia. These findings are in line with the findings of Neal et al.⁴¹'s systematic review, which also found insufficient evidence to draw conclusions about the impact of technology on the social participation of people with dementia.

Several factors contribute to this limited body of evidence. Firstly, there is a notable lack of technological intervention studies in the dementia context that include social participation as a primary outcome,⁴¹ possibly linked to the aforementioned challenges in measuring social participation within intervention trials. Secondly, it was observed that only limited technologies have been specifically designed to promote social participation in dementia (**Chapter 4**), which is in line with other studies that also found only limited availability of technologies targeting the social needs of people with dementia.^{42,43} Thirdly, our systematic review revealed that technological interventions targeting older adults with and without dementia applied mostly pilot trial approaches, including small sample sizes and limited methodological quality, which subsequently impacts the capacity to draw conclusions regarding their effectiveness. Similar trends are observed in other reviews.^{41,44} This might be attributed to the rapid pace of technological developments, where the traditional randomized controlled trial (RCT) approach may result in outdated interventions by the time trials are completed. Therefore, it is important to consider alternative study designs, taking into account the trade-offs between internal and external validity, resource and time constraints, and specific research questions. Embedded pragmatic trials (ePCTs), for instance, may better reflect real-world conditions and offer faster results, although they may present limitations in controlling for bias compared to traditional RCTs.^{45,46}

One major finding of our thesis is the need for technology to be adaptive to the needs of people with dementia (**Chapter 5**) and the way an individual adapts to changes in social participation (**Chapters 2 and 3**). Firstly, this finding highlights the valuable role occupational therapists could play in the development of technological interventions and the need for them to continue to be acquainted with such technologies through continuous professional development and education (**Chapter 6**). Secondly, this finding highlights a missed opportunity in **Chapter 5** for the co-development of a technological intervention with people with dementia and their informal caregivers.⁴⁷ Nonetheless,

conducting a feasibility study with an existing system, even one originally designed for a different target group,⁴⁸ as opposed to developing a new system through a co-design process, offers several advantages, primarily centred around the tangible nature of an existing system. The involvement of a tangible system provides people with dementia and their informal caregivers with a means to understand and express their preferences, needs, and concerns.⁴⁹ Additionally, it facilitates gaining a deeper understanding of how the technology fits into their daily lives and routines. These contextual insights can inform the quality of their feedback, helping designers and researchers understand the practical implications of their design choices. Furthermore, using an existing system often proves to be more efficient in terms of both time and resources.

METHODOLOGICAL CONSIDERATIONS

While this thesis advances our understanding of the concept of social participation in dementia, as well as the potential effects of technological interventions in promoting it, certain limitations have to be considered.

Strengths

This thesis holds several notable strengths. It encompasses different perspectives and knowledge drawn from diverse backgrounds, including neuropsychology, occupational therapy, neuropsychiatry, and transportation sciences. Thereby, it advances the field in the understanding of social participation in dementia, as well as the potential of technology in addressing it. Furthermore, it offers implications for both future research and practice.

Another noteworthy strength of this thesis lies in the variety of applied research methodologies, combining findings resulting from a mixed methods study, qualitative interviews, literature reviews, and a feasibility trial. A majority of these research methodologies allowed for the inclusion of the perspectives of people with dementia and their informal caregivers, reinforcing the credibility of the study findings. Moreover, this thesis included a Patient and Public Involvement (PPI) consultation with members of the European Working Group of People with Dementia (EWGPWD) to ensure that interview questions were considerate and relevant for people with dementia and their spouses (**Chapter 3**). PPI is defined as research carried out with or by members of the public rather than about or for them.⁵⁰

Limitations

The limitations of this thesis have to be acknowledged. The relatively small sample sizes in **Chapters 2 and 5** pose challenges to the generalizability of study findings. **Chapter 5**, in particular, encountered recruitment challenges, despite the employment of diverse recruitment strategies. Other studies including people with dementia encountered similar challenges, such as informal caregivers acting as protective gatekeepers and difficulties with smartphone use among people with dementia.^{51,52} Additionally, a recruitment bias may have occurred, given that the studies described in **Chapters 3 and 5** exclusively included people with dementia who had an informal caregiver available and still took part in social activities outside the home. As a result, people with dementia with smaller social networks who may experience greater social isolation were unintentionally excluded. Furthermore, certain target groups are underrepresented in these chapters, such as individuals with dementia from ethnic minority groups or those living with dementia in employment. The inclusion of dyads may also have introduced a response bias, possibly limiting the capture of spouses' perspectives during interviews. To mitigate this, the interviewer relied on non-verbal cues to capture individual perspectives.

In **Chapter 5**, a notable limitation concerns the lack of a co-creation development process, which resulted in a mismatch between the features of the technological intervention *Viamigo* and the actual needs of people with dementia and their informal caregivers. The chapter did not adhere to the recommendations of the Medical Research Council (MRC) framework for the development and evaluation of complex interventions,^{53,54} thereby missing the opportunity for an iterative development process. However, a previous study by McCabe and Innes⁴⁹ reported that study participants found it challenging to articulate their needs and requirements when talking about a GPS intervention hypothetically. Instead, our study allowed participants to provide context-driven feedback on the *Viamigo* intervention, which proved valuable for informing future technological enhancements and developments.

Another limitation pertains to the data collection in **Chapters 2, 3 and 5**, which was performed within participants' homes. While this approach aligns with recommendations that highlight the importance of capturing the experiences of people with dementia in a familiar and comfortable environment,⁵⁵ it may have impacted the ecological validity of the research. Given that **Chapters 2 and 3** revolved around out-of-home social participation, the incorporation of walking interviews may have complemented data collection processes.^{16,56} Similarly, the incorporation of think-aloud sessions or observations to assess the feasibility and acceptability of the *Viamigo* intervention may have yielded more context-specific study findings in **Chapter 5**.⁴⁷

IMPLICATIONS

Our findings from **Chapters 2 and 3** have significant implications for the design of dementia-friendly communities and society at large. They highlight the imperative need to create an inclusive environment, wherein people with dementia can feel treated as human beings, are shielded from stigma, and can continue to participate in social activities that are meaningful for them. When designing dementia-friendly communities, it is essential to create an environment that permits tailored adaptation, aligning with the individual abilities, wishes and needs of people with dementia. Furthermore, it is important to recognise that people with dementia actively choose occupations that reinforce their identity within environments that provide a sense of comfort and safety (i.e., familiar environments). Rather than creating separate environments and activities exclusively for people with dementia, thoughtful consideration should be given to the adaptation of existing activities and environments to improve inclusivity for people with dementia.

Furthermore, our findings hold implications for the development of technological interventions aimed at enhancing social participation among people with dementia. They emphasize the importance of tailoring technology to the individual's changing needs, abilities, and preferences (**Chapters 5 and 6**). Given the rapid developments in Artificial Intelligence (AI), AI could play an important role in the future development of technologies that can dynamically adapt to the changing needs and abilities of people with dementia, continuing to support them in their social participation.⁵⁷ In addition, our findings highlight the importance of co-design in technology development, involving all relevant stakeholders. Ideally, people with dementia and their informal caregivers should be included in the early stages of development. However, in case of time and resource constraints, providing them with existing technology that is not yet tailored to their individual needs can facilitate the needs assessment phase. Additionally, occupational therapists emerge as relevant stakeholders in the development process. Therefore, efforts should be directed towards integrating social participation technology into clinical practice and education for future healthcare professionals, including occupational therapists.

FUTURE RESEARCH DIRECTIONS

Overall, this thesis adds to the scientific understanding of social participation in dementia and the role technology could play therein. Nonetheless, it also underscores the imperative need for future research to delve into several critical aspects.

Measuring social participation in dementia

Our findings highlight the importance of adopting a more individualized approach to measuring social participation in intervention trials, accounting for the individual and diverse contextual factors that influence it. To facilitate meaningful cross-study comparisons of psychosocial interventions targeting people with dementia, more research is therefore needed into outcome measures that look into individuals' adaptability to changes in social participation and their overall satisfaction.

Promoting social participation among people with dementia with limited social networks

An observable gap in current studies remains in the lack of inclusion of individuals with dementia who experience a high degree of social isolation at baseline (**Chapter 4**). Additionally, **Chapters 3 and 5** of this thesis included dyads consisting of a person with dementia and an informal caregiver, inadvertently missing out on the perspectives of people with dementia who are living alone and do not have a loved one available for study participation. Moreover, our findings (**Chapters 2 and 3**) highlight the importance of social network support in achieving a higher level of independence in social participation. Therefore, there is a compelling need for research to explore how this specific target group adapts to changes in social participation and, thereby, to identify ways to foster their social participation. Challenges in recruiting such study participants (**Chapter 4**) necessitate innovative recruitment methods.

Effects of technological interventions among people with dementia

While this thesis contributes valuable insights into the potential role of technology in promoting social participation among people with dementia, it also underscores the limited scope of studies evaluating the effects of technological interventions among this target population (**Chapter 4**). With a rapidly evolving technological landscape, there is a need to further explore these effects. Given that social participation seeks to facilitate involvement in activities in the community (58), more studies should delve into the use of technological interventions to facilitate participation in out-of-home activities.

The potential role of occupational therapists in personalising technology

Our findings highlight the need for technologies to be tailored to the individual needs, routines, and preferences of people with dementia and their informal caregivers (**Chapter 5**). Occupational therapists hold the potential to play an important role in the development of tailored technologies, yet their current role in the development and implementation of technology remains somewhat limited (**Chapter 6**). Thus, there is a need for future research to identify strategies that reinforce the involvement of occupational therapists in this domain, thereby strengthening their contribution to personalized technology solutions for people with dementia.

CONCLUDING REMARKS

This thesis highlights the capacity of people with dementia to adapt to changes in social participation, thereby gaining a sense of autonomy in control. Although technology might have added value in promoting social participation among people with dementia, there remains a limited body of evidence regarding its effectiveness. This thesis underscores the importance of tailoring technology to accommodate the individual and changing needs, preferences, and abilities of people with dementia. Additionally, it recognises the valuable role that occupational therapists could play therein. Future research should focus on exploring social participation experiences among people with dementia with limited social support, developing individualised outcome measures for social participation, further exploring the effects of technological intervention on people with dementia, and exploring the potential involvement of occupational therapists in tailoring technology for people with dementia.

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ADDENDUM

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 underscored 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.

NEDERLANDSE SAMENVATTING

Sociale participatie is een relevante voorspeller van succesvol ouder worden en goed leven met dementie. Het is geassocieerd met verschillende positieve effecten, waaronder verbeterde gezondheid, hogere levenstevredenheid en een versterkt gevoel van autonomie en identiteit. Mensen met dementie ervaren echter vaak een afname in sociale participatie en ultiem onvervulde sociale behoeften. Dit wijst op de dringende noodzaak van interventies gericht op sociale participatie. Vanwege de recente technologische ontwikkelingen heeft het gebruik van technologie aanzienlijke aandacht gekregen ter bevordering van sociale participatie. Hoewel technologie op dit gebied potentieel heeft, is de wetenschappelijke literatuur beperkt. Daarom heeft dit proefschrift tot doel de ervaringen van sociale participatie bij dementie in kaart te brengen en de potentiële rol te verkennen die technologie daarin kan spelen. Het is verdeeld in twee delen: deel I onderzocht de ervaringen van sociale participatie bij mensen met dementie, terwijl deel II zich richtte op de potentiële toegevoegde waarde die technologie kan bieden bij het bevorderen ervan.

Deel I: Ervaringen van sociale participatie bij dementie

Hoofdstuk 2 draait om de ervaringen van thuiswonende mensen met dementie met betrekking tot hun sociale participatie buiten de deur. Een mixed methods benadering werd gebruikt om hun zorgen en overwegingen te verkennen. Hoewel deelnemers weinig zorgen uitten over het deelnemen aan sociale activiteiten buiten de deur, waren ze zich zeer bewust van de uitdagingen en risico's die ze tegenkwamen. Om met deze uitdagingen om te gaan, waren deelnemers alerter en attenter op bepaalde aspecten, zoals de weg te vinden, niet te vallen en op hun spullen te letten. Deze bevindingen benadrukken hoe thuiswonende mensen met dementie hun eigen vaardigheden en capaciteiten inzetten om zich succesvol aan te passen aan uitdagingen in hun sociale participatie.

Hoofdstuk 3 ging dieper in op deze aanpassingsprocessen met behulp van dyadische interviews met thuiswonende mensen met dementie en hun partners. Een belangrijke bevinding was dat deelnemers met dementie actief kozen voor omgevingen die de voortzetting van sociale participatie ondersteunden, zoals vertrouwde plaatsen of mensen die hen begrepen en als mens behandelden. Partners zochten in de veranderende wereld van sociale participatie een evenwicht tussen hun huidige en vroegere rollen, net zoals een evenwicht tussen hun eigen behoeften op het gebied van sociale participatie en die van hun naasten met dementie.

Deel II: Technologie en sociale participatie bij dementie

Om de toegevoegde waarde van technologie bij het bevorderen van sociale participatie bij ouderen met en zonder dementie te verkennen, werd een systematische review uitgevoerd (**hoofdstuk 4**). Een belangrijke bevinding was de inconsistentie van geïncludeerde studies in de operationalisering van sociale participatie. Dit gebrek aan consistentie beïnvloedt de vergelijkbaarheid van de onderzoeksresultaten. Bovendien onderstrepten de bevindingen van de review het beperkte bewijsmateriaal op dit gebied, waarbij slechts drie studies specifiek gericht waren op mensen met dementie. Hoewel deze bevindingen lieten zien dat technologische interventies beloftevol zijn om eenzaamheid te verminderen en sociale ondersteuning te verbeteren bij cognitief gezonde ouderen, konden er geen conclusies worden getrokken over hun effectiviteit bij mensen met dementie.

In **hoofdstuk 5** werd de haalbaarheid en acceptatie van een op een Geografisch Informatie Systeem (GIS) gebaseerde mobiele applicatie ('Viamigo') geëvalueerd bij mensen met dementie en hun partners. Dit haalbaarheidsonderzoek liet zien dat er behoefte was aan technologie die was afgestemd op de individuele en unieke behoeften van individuen met dementie en hun partners. Het hoofdstuk benadrukt het belang van het betrekken van mensen met dementie in het ontwikkelingsproces van technologie om deze beter af te stemmen op hun voorkeuren en behoeften.

Met het oog op het belang van het afstemmen van technologie voor sociale participatie op individuele behoeften, besprak **hoofdstuk 6** de potentiële rol die ergotherapeuten hierin kunnen spelen. Het hoofdstuk benadrukt de unieke vaardigheden van ergotherapeuten bij het adviseren over het personaliseren van technologie om te voldoen aan de behoeften van mensen met dementie. Daarnaast reflecteert het op de vaardigheden van ergotherapeuten bij het voortdurend adviseren van het gebruik van technologie in het dagelijks leven. Het hoofdstuk formuleert aanbevelingen voor de praktijk, waarbij de noodzaak van samenwerking tussen alle relevante belanghebbenden van het ontwikkelings- en implementatieproces wordt benadrukt, zoals ergotherapeuten, onderzoekers, technologieontwikkelaars en mensen met dementie.

In **hoofdstuk 7** worden de belangrijkste bevindingen van dit proefschrift besproken, samen met methodologische overwegingen en implicaties voor de praktijk en toekomstig onderzoek.

ZUSAMMENFASSUNG

Soziale Teilhabe spielt im Prozess des gesunden Alterns und in der Gestaltung eines erfüllten Lebens mit Demenz eine entscheidende Rolle. Die Beteiligung am sozialen Leben wirkt sich positiv auf verschiedene Aspekte aus, darunter verbesserte Gesundheit, Lebenszufriedenheit und einem gestärkten Gefühl von Autonomie und Identität. Bei Menschen mit Demenz kommt es jedoch oft zu einem Rückgang der sozialen Teilhabe und zur Äußerung unerfüllter sozialer Bedürfnisse. Dies unterstreicht die dringende Notwendigkeit von Maßnahmen zur Förderung der sozialen Teilhabe. In Anbetracht der raschen technologischen Fortschritte der letzten Jahre ist der Einsatz von Technologie zur Förderung der sozialen Teilhabe in den Fokus gerückt. Obwohl Technologie in diesem Bereich Potenzial birgt, ist die wissenschaftliche Literatur zu diesem Thema begrenzt. Daher ist das Hauptziel dieser Arbeit, ein besseres Verständnis für die Erfahrungen der sozialen Teilhabe bei Demenz zu erlangen und die potenzielle Rolle von Technologie in diesem Kontext zu erforschen. Die Arbeit ist in zwei Teile gegliedert: Teil I untersucht die Erfahrungen der sozialen Teilhabe bei Demenz, während Teil II den potenziellen Mehrwert von Technologie in diesem Bereich analysiert.

Teil I: Erfahrungen der sozialen Teilhabe bei Demenz

Kapitel 2 befasst sich mit den Erfahrungen von Menschen mit Demenz im häuslichen Setting im Hinblick auf ihre soziale Teilhabe außerhalb des Hauses. Ein Mixed-Methods-Ansatz wurde verwendet, um die Überlegungen und Sorgen der TeilnehmerInnen bei sozialen Aktivitäten außerhalb des Hauses zu erforschen. Obwohl TeilnehmerInnen nicht besonders besorgt waren, waren sie sich der Herausforderungen und Risiken, denen sie gegenüberstanden, sehr bewusst. Um diese Herausforderungen zu bewältigen, mussten die TeilnehmerInnen auf bestimmte Aspekte achten, wie den Weg zu finden, nicht zu stolpern und die Wertsachen im Auge zu behalten. Die Ergebnisse zeigen auf, wie Menschen mit Demenz im häuslichen Setting ihre Fähigkeiten nutzen, um sich erfolgreich an die Herausforderungen im Rahmen ihrer sozialen Teilhabe anzupassen.

Kapitel 3 erforscht diese Anpassungsprozesse durch dyadische Interviews mit Menschen mit Demenz und ihren PartnerInnen in den eigenen vier Wänden. Eine wichtige Erkenntnis war, dass TeilnehmerInnen mit Demenz aktiv Umgebungen wählten, die den Erhalt ihrer sozialen Teilhabe unterstützten, wie vertraute Orte oder Menschen, bei denen sie sich verstanden und als Mensch fühlten. PartnerInnen beschrieben die sich verändernde Welt der sozialen Teilhabe als Balanceakt, bei dem sie ein Gleichgewicht anstreben zwischen ihren momentanen und vergangenen Rollen und ebenfalls zwischen ihren eigenen Bedürfnisse nach sozialer Teilhabe und denen ihrer PartnerInnen.

Teil II: Technologien und soziale Teilhabe bei Demenz

Um den potenziellen Mehrwert von Technologie zur Förderung der sozialen Teilhabe älterer Menschen mit und ohne Demenz zu erkunden, wurde ein Systematic Review durchgeführt (**Kapitel 4**). Eine wichtige Erkenntnis war die Inkonsistenz der eingeschlossenen Studien bei der Definierung und Operationalisierung von dem Konzept der sozialen Teilhabe. Diese Inkonsistenz beeinflusst die Vergleichbarkeit der Studienergebnisse. Darüber hinaus betonen die Ergebnisse der Literaturstudie den begrenzten Forschungsumfang auf diesem Gebiet, da nur drei Studien identifiziert wurden, die sich speziell auf Menschen mit Demenz richteten. Während die Ergebnisse des Kapitels darauf hinwiesen, dass technologische Interventionen vielversprechend sind, um Einsamkeit zu lindern und soziale Unterstützung bei kognitiv gesunden älteren Menschen zu fördern, konnten keine Schlussfolgerungen hinsichtlich ihrer Wirksamkeit bei Menschen mit Demenz gezogen werden.

In **Kapitel 5** wurde die Machbarkeit und Eignung einer, auf einem geografischen Informationssystem basierenden, mobilen Anwendung („Viamigo“) bei Menschen mit Demenz und ihren PartnerInnen evaluiert. Eine wichtige Erkenntnis dieser Machbarkeitsstudie war die Notwendigkeit, Technologie auf die individuellen und einzigartigen Bedürfnisse von Menschen mit Demenz und ihren Angehörigen zuzuschneiden. Das Kapitel betont die Bedeutung der Partizipation von Menschen mit Demenz während des Entwicklungsprozesses von Technologie, um diese besser an ihre Bedürfnisse und Vorlieben anzupassen.

Kapitel 6 diskutiert die potenzielle Rolle von ErgotherapeutInnen bei der Anpassung von Technologien an die individuellen Bedürfnisse von Menschen mit Demenz und ihren Angehörigen. Es hebt die einzigartigen Fähigkeiten von ErgotherapeutInnen hervor, die Anpassung und Personalisierung von Technologie zur Bewältigung des Alltags von Menschen mit Demenz zu beraten. Darüber hinaus reflektiert es die Fähigkeiten von ErgotherapeutInnen bei der fortlaufenden Evaluierung des Technologieeinsatzes im täglichen Leben. Das Kapitel endet mit praktischen Empfehlungen und betont die Notwendigkeit der Zusammenarbeit zwischen allen relevanten Beteiligten am Entwicklungs- und Einführungsprozess von Technologien, wie ErgotherapeutInnen, ForscherInnen, Technologie-EntwicklerInnen und Menschen mit Demenz.

In **Kapitel 7** werden die Hauptergebnisse zusammen mit methodischen Überlegungen und Implikationen für die Praxis und zukünftige Forschung diskutiert.

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.

LIST OF PUBLICATIONS

This thesis

Koh WQ, **Heins P**, Flynn A, Mahmoudi Asl A, Garcia L, Malinowsky C, & Brorsson A. Bridging gaps in the design and implementation of socially assistive technologies for dementia care: The role of occupational therapy. *Disabil Rehabil: Assist Technol*. 2022;1-9.

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Heins P, Malinowsky C, Boots LMM, de Vugt ME, & Brorsson A. People with dementia being out and about: A mixed methods study on out-of-home social participation. *Submitted*.

Heins P, Kohl G, Neven A, Verhey FRJ, de Vugt ME, & Boots LMM. Social participation outside the home, a changing world: a qualitative interview study on the experiences of people with dementia and their informal caregivers. *Submitted*.

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Kohl G, Cardoso S, **Heins P**, Scior K, & Charlesworth G. Guidance for moving psychosocial interventions online: a worked example of adapting 'Who to tell, how and when' for people living with dementia. *In preparation.*

Thesis defences from the school for mental health and neuroscience (mhens)

2024

Jennifer Monereo-Sánchez. **Segmenting the human brain in population bases studies: Methodological considerations and clinical applications in diabetes, depression, and dementia.** Supervisors: Prof. dr. D.Linden; Dr. M. Schram; Dr. J. Jansen.

Lieke Bakker. **The Kynurenine Pathway and Cognitive Functioning: A Transdiagnostic Approach.** Supervisors: Dr. S. Köhler; Prof. dr. F. Verhey. Co-supervisor: Dr. I. Ramakers; Dr. S. Eussen.

Shuhe Zhang. **Single Retinal Image Restoration.** Supervisors: Prof. dr. C.A. Webers; Dr. T.T. Berendschot. Co-supervisor: Dr. R. Duits (Eindhoven University of Technology).

Agorastos Agorastos. **The balance within: Factors influencing neurovisceral autonomic responsiveness to endocrine and pharmacological stress challenges.** Supervisor: Prof. dr. K. Schruers. Co-supervisor: Dr. N. Leibold.

Michel van Hooren. **The impact of oropharyngeal dysphagia and dysphonia on health-related quality of life in Parkinson's disease.** Supervisors: Dr. L.W.J. Baijens; Prof. dr. B. Kremer. Co-supervisor: Dr. W. Pilz.

Stella Voulgaropoulou. **Modeling the brain: Mechanisms underlying the interplay between the multiple facets of stress and cognition.** Supervisor: Prof. dr. T. van Amelsvoort. Co-supervisors: Dr. D. Hernaus; Dr. C. Vingerhoets.

Carmen van Hooijdonk. **On the bumpy road of psychotic disorders: Paving new avenues for personalized treatment approaches by examining neurochemical changes in psychosis and related disorders.** Supervisors: Prof. dr. T. van Amelsvoort; Prof. dr. J.P. Selten; Prof. dr. J. Booij (Amsterdam UMC).

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Hannah Bernhard. **In The Event Of Memory: Behavioral and brain processes supporting the formation of episodic memories.** Supervisors: Prof. dr. P. de Weerd; Dr. J. Reithler. Co-supervisor: Dr. R. Rouhl.

Sriganesh Kamath. **Assessment and management of perioperative pain in neurosurgical patients.** Supervisors: Prof. dr. H.W.M. Steinbusch; Prof. dr. T.N. Satyaprabha (Bangalore); Prof. dr. G.S. Umamaheswara Rao (Bangalore).

Zeinab Mamdouh. **De-novo construction of organ-agnostic cancer modules and therapeutic application.** Supervisor: Prof. dr. H.H.H.W. Schmidt. Co-supervisor: Dr. C. Nogales Calvo.

Dean Paes. **Picking the best isoform PDE4D isoforms as therapeutic targets in Alzheimer's disease.** Supervisors: Prof. dr. D. van den Hove; Dr. T. Vanmierlo (Hasselt University). Co-supervisor: Prof. dr. N. Hellings (Hasselt University).

Emma von Scheibler. **Characterization of genetic neurodevelopmental disorders at adult age, with a focus on 22q11.2 deletion syndrome.** Supervisor: Prof. dr. T.A.M.J. van Amelsvoort. Co-supervisors: Dr. H.J.G. Boot; Dr. A.M. van Eeghen (University of Amsterdam).

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Jessica Berkvens. **Osteoporosis and fractures in institutionalized patients with refractory epilepsy and intellectual disability.** Supervisors: Prof. dr. H.J.M. Majoie; Prof. dr. J.P.W. van den Bergh. Co-supervisor: Dr. S. Mergler (Erasmus MC Rotterdam).

Irene Moll. **Cerebral Palsy: Cognition, fatigue and assessing functional electrical stimulation during walking.** Supervisor: Prof. dr. R. Vermeulen. Co-supervisor: Dr. K. Meijer.

Lonne Heijmans. **Paresthesia free spinal cord stimulation in experimental chronic neuropathic pain.** Supervisors: Prof. dr. E. Joosten; Prof. dr. J. van Zundert.

Miriam Fichtner. **Features of muscle-specific tyrosine kinase autoantibodies and B cells derived from myasthenia gravis patients.** Supervisors: Prof. dr. P. Martinez; Prof. dr. K. O'Connor (Yale University, USA). Co-supervisor: Dr. M. Losen.

Lambertus Verheijen. **The Ubiquitin-Proteasome System in Neurodegenerative Diseases: Lessons from Mutant Ubiquitin.** Supervisors: Prof. dr. H.W.M. Steinbusch; Prof. dr. D.A. Hopkins (Dalhousie University, Canada). Co-supervisor: Dr. F.W. van Leeuwen.

Isis Joosten. **Myotonic dystrophy type 1 Clinical genetics and multisystem involvement.** Supervisors: Prof. dr. C. Faber; Prof. dr. K. Vernooy; Prof. dr. L. van Loon.

Martijn Mons. **Neuromodulation in nonoperated discogenic low back pain: efficacy and mechanism.** Supervisors: Prof. dr. E. Joosten; Prof. dr. J. van Zundert. Co-supervisor: Dr. J.W. Kallewaard.

Ralf van Mechelen. **Preclinical validation of antifibrotic implantables for use in bleb-forming glaucoma surgery.** Supervisor: Prof. dr. H. Beckers. Co-supervisors: Dr. J. Wolters (Medpace Medical Device B.V.); Dr. C. Bertens.

Mathew Francis. **A Comprehensive Study of Corneal Tissue Responses to Customized Surgical Treatments.** Supervisors: Prof. dr. R. Nuijts; Dr. R. Shetty (Narayana Nethralaya Eye Hospital, Bangalore, India). Co-supervisor: Dr. A.S. Roy (Narayana Nethralaya Foundation, Bangalore, India).

Laila Hasmi. **Network complexity modelling of psychopathology to encompass symptoms, genetic and environmental influences.** Supervisors: Prof. dr. J. van Os; Prof. dr. S. Guloksuz. Co-supervisor: Dr. M. Drukker.

Jurriaan Brekelmans. **New developments in the treatment of corneal ectatic disorders.** Supervisor: Prof. dr. R. Nuijts. Co-supervisors: Dr. M. Dickman; Prof. dr. A. Marcovich (Kaplan Medical Center, Israel).

Haang Jeung-Maarse. **Impairments in Social Interaction of Individuals with Personality Disorders and Dark Personality Traits.** Supervisors: Prof. dr. K. Schruers; Prof. dr. C. Schwieren (Heidelberg University, Germany).

Pere Català Quilis. **Understanding the complexity of the corneal endothelium for regenerative medicine.** Supervisor: Prof. dr. R. Nuijts. Co-supervisors: Dr. V. LaPointe; Dr. M. Dickman.

Suryan Leif Dunker. **Current State of Endothelial Keratoplasty.** Supervisor: Prof. dr. R. Nuijts. Co-supervisors: Dr. M. Dickman; Dr. F. van den Biggelaar.

Anneke Terneusen. **KNOW THYSELF - Theoretical and Neurobehavioral Perspectives on Self-Awareness.** Supervisors: Prof. dr. C. van Heugten; Prof. dr. R. Ponds. Co-supervisor: Dr. I. Winkens.

Ghazi Al Jowf. **Biomedical and Public Health Studies on Susceptibility to Post-Traumatic Stress Disorder.** Supervisor: Prof. dr. B. Rutten. Co-supervisors: Dr. L. Eijssen; Dr. L. de Nijs.

Faisal Mohammed Alosaimi. **Monoaminergic neurotransmitter systems underlie therapeutic and side effects of deep brain stimulation.** Supervisors: Prof. dr. Y. Temel; Dr. A. Jahanshahi. Co-supervisor: Dr. S.-A. Hescham.

Cai Zhang. **Immunotherapy: a potential treatment strategy for depression.** Supervisors: Prof. dr. H.W.M. Steinbusch; Prof. dr. T.D. Charlier (University of Rennes, Rennes, France); Prof. dr. C. Song (Guangdong Ocean University, Zhanjinag, PRC). Co-supervisor: Dr. J. Pawluski (University of Rennes, Rennes, France).

Milena Agata Ślęczkowska. **Genetics of neuropathic pain: the emerging role of variants in ion channels and pain-related genes.** Supervisors: Prof. dr. H.J.M. Smeets; Prof. dr. C.G. Faber. Co-supervisor: Dr. M.M. Gerrits.

Maurice Sopacua. **Improving assessments in the Diagnosis of Small Fiber Neuropathy.** Supervisors: Prof. dr. C.G. Faber; Prof. dr. I.S.J. Merkies. Co-supervisor: Dr. J.G.J. Hoeijmakers.

Jackson Boonstra. **Neuroanatomical Variation in Parkinson's Disease Motor Subtypes.** Supervisors: Prof. dr. Y. Temel; Dr. A. Jahanshahi. Co-supervisor: Dr. A. Roebroek.

Mathew Francis. **A Comprehensive Study of Corneal Tissue Responses to Customized Surgical Treatments.** Supervisors: Prof. dr. R.M.M.A. Nuijts; Dr. R. Shetty (Narayana Nethralaya Eye Hospital, Bangalore, India). Co-supervisor: Dr. A.S. Roy (Narayana Nethralaya Foundation, Bangalore, India).

Assia Tiane. **Relieving the epigenetic blockade in progressive MS – making remyelination accessible again.** Supervisors: Prof. dr. T. Vanmierlo (Universiteit Hasselt); Prof. dr. D. van den Hove. Co-supervisors: Prof. dr. N. Hellings (Universiteit Hasselt); Prof. dr. J. Prickaerts.

Alexandra Petraina. **Mechanism-based diagnosis of cyclic GMPopathies and pharmacological interventions.** Supervisor: Prof. dr. H.H.H.W. Schmidt. Co-supervisor: Dr. C. Nogales Calvo.

Katherine Christophe Bassil. **Stress in a dish - Modeling the neurobiology of glucocorticoids in vitro, investigating stress susceptibility, and highlighting ethical implications.** Supervisor: Prof. dr. B.P.F. Rutten. Co-supervisors: Dr. G. Kenis; Dr. L.C.C. de Nijs.

Samantha Baldi. **On Connecting Dots: From imaging to stimulating the obsessive-compulsive brain.** Supervisor: Prof. dr. K.R.J. Schruers. Co-supervisors: Dr. L. Goossens; Dr. T. Schuhmann.

Melissa Schepers. **PDE4 gene inhibition – a novel approach to treat demyelinating disorders.** Supervisors: Prof. dr. T. Vanmierlo; Prof. dr. J. Prickaerts. Co-supervisors: Prof. dr. N. Hellings; Prof. dr. B. Rutten.

Jeanette Tas. **Next Generation Neuromonitoring Multimodality, Cerebral Autoregulation and a Refined Outcome in Severe Traumatic Brain Injury.** Supervisors: Prof. dr. J.C.C. van der Horst; Prof. dr. C.M. van Heugten. Co-supervisor: Dr. M.J.H. Aries.

Mathijs de Rijk. **Interactive control of the lower urinary tract: Translational models in functional and neuro-urology.** Supervisors: Prof. dr. G. van Koeveeringe; Prof. dr. L. Birder (University of Pittsburgh, United States). Co-supervisors: Dr. J. van den Hurk; Dr. S. Rahnama'i.

Annelie Tan. **Outcome and safety of the Baerveldt glaucoma implant.** Supervisors: Prof. dr. H.J.M. Beckers; Prof. dr. C.A.B. Webers; Prof. dr. G.P.M. Luyten (Leiden UMC). Co-supervisor: Dr. T.T.J.M. Berendschot.

Manon van den Berg. **Translational Research Investigating Psilocybin: Underlying neurobiological mechanisms.** Supervisors: Prof. dr. J. Prickaerts; Prof. dr. J.G. Ramaekers; Prof. E. Fedele (University of Genoa). Co-supervisor: Dr. J.J. Briedé.

Thesis defences from MHeNs from previous years can be found via the following link: <https://www.maastrichtuniversity.nl/research/overview-our-latest-and-upcoming-phd-defence>

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“We’re all in this together”

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“I am sure we can find a way to have fun while we get this job done.”

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„A friend like you always makes it easy.“

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„It’s brought us here because you are the music in me.“

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„And the world looks so much brighter with you by my side.“

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ABOUT THE AUTHOR

Pascale Heins was born on April 2 1994 in Eupen, Belgium. In 2016, she earned a Bachelor of Science degree in Occupational Therapy from Hogeschool Zuyd in Heerlen, the Netherlands. During her undergraduate studies, Pascale developed a passion for exploring the intersection of dementia and technology. Continuing her academic pursuit, Pascale completed a Master of Science in Health Assisting Engineering at FH Campus Wien in Vienna, Austria, in 2019. Simultaneously, she worked as an occupational therapist for two years in a residential care home, specializing in providing care for individuals living with dementia.



Driven by a commitment to research and improving the lives of those living with dementia, Pascale pursued a PhD at Maastricht University, joining the Alzheimer Centre Limburg within the Department of Psychiatry and Neuropsychology. Under the guidance of Prof. Dr. Marjolein de Vugt, Prof. Dr. Frans Verhey, Dr. Lizzy Boots, and Dr. An Neven, her doctoral research delved into understanding the experiences of social participation in dementia, and the potential role of technology therein. This PhD took place as part of the Marie-Skłodowska-Curie Innovative Training Network DISTINCT (Dementia: Intersectorial Strategy for Training and Innovation Network for Current Technology).

Currently working as a Postdoctoral Researcher at the Alzheimer Centrum Limburg, Pascale is actively engaged in academia. She co-chairs the ISTAART Professional Interest Area to Elevate Early Career Researcher (PEERs), organises workshops for Early Career Researchers in collaboration with INTERDEM Academy and ISTAART. Simultaneously, she initiated her occupational therapy practice within the franchise company *Ergotherapiepraktijk Zuid-Limburg* in January 2024. Here, she primarily works with older people, including those living with dementia, helping them to be more independent in their daily life. This dual commitment reflects her dedication to both advancing academic research and making a positive impact on the lives of individuals through clinical practice. Furthermore, Pascale volunteers at the Alzheimer Café Maastricht.

