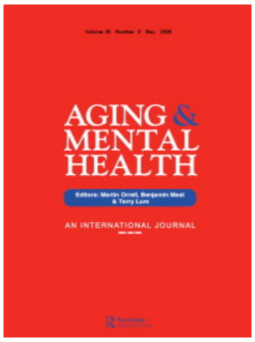

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# Navigating a changing world of social participation: a qualitative interview study with people with dementia and their informal caregivers

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**ABSTRACT**

**Objectives:** This study explored the social out-of-home participation experiences of people with dementia and their informal caregivers from a capability-based approach.

**Method:** Twelve dyadic interviews with people with dementia living in the community and their informal caregivers were conducted. Data were inductively coded using a reflexive thematic analysis approach.

**Results:** All participants with dementia experienced changes in activities, social interactions or out-of-home mobility, captured in the overarching theme of *'social participation: a changing world'*. Four subthemes captured the primary strategies participants used to navigate these changes: (1) creating a sense of comfort and safety in nearby, quiet, and familiar places; (2) pursuing a sense of social identity through meaningful connections; (3) accepting support to maintain independence; and (4) finding a balance, as described by informal caregivers, between their own social needs and those of their spouses. These themes highlight the agency of people with dementia in shaping their social participation amid changes in capabilities and environments.

**Conclusion:** This study contributes to a more nuanced understanding of social participation in dementia, emphasising the importance of supportive environments that recognise both capabilities and needs can enable continued engagement and foster social health.

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Dementia; social participation; social health; community; informal caregiver

## Introduction

Dementia is a major cause of dependence and disability among older adults (WHO, 2022). More than 55 million people worldwide live with dementia. This number is likely to increase in the forthcoming decades (GBD 2019 Dementia Forecasting Collaborators, 2022), along with the costs of long-term care (Francke et al., 2018). National authorities facilitate ageing-in-place, which has resulted in a large portion of people with dementia living in the community (European Commission, 2018). A scoping review identified that participation in meaningful activities, social company, and social opportunity are the most commonly reported unmet needs among people with dementia living in the community (Morrisby et al., 2018). Its findings highlight the importance of finding ways to empower people with dementia to participate in community life and meet their social participation needs.

Social participation, a dimension of social health, is defined as the ability to take part in social activities (Huber et al., 2011). In the dementia context, it has been operationalised as 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' (Dröes et al., 2017, p. 9). More recently, Levasseur et al. (2022) defined social participation as 'a person's involvement in activities providing interactions with others in community life and 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). In this study, we primarily draw on the definition by Levasseur et al. (2022), as it centers on what individuals themselves want and find meaningful, while also recognising the evolving nature of participation in relation to personal resources and social context. In people with dementia, social participation has been found to promote social connectedness (Han et al., 2016) and provide a sense of autonomy and identity (Odzakovic et al., 2020; Olsson et al., 2013).

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An essential element of social participation in community life involves participation in activities outside the home. While the United Nations Convention on the Rights of Persons with Disabilities emphasises the rights of people with dementia to fully participate in all aspects of life (United Nations, 2006), they often face barriers to out-of-home participation. In an often-cited interview study on challenges and barriers to out-of-home participation in dementia, Duggan et al. (2008) described that people with dementia experience a 'shrinking world', both in terms of the frequency of out-of-home activities they engage in and the number of places outside the home they visit. The authors suggest that people with dementia are impaired by dementia symptoms like disorientation in accessing places outside the home in which they feel comfortable, and become therefore increasingly dependent on others in their out-of-home participation, which can result in a decline in independence and control (Duggan et al., 2008). Studies confirm that people with dementia are likely to experience a decline in participation in activities and places outside the home (Gaber et al., 2022) and are more dependent on others for participating in activities that require transportation by car or public transportation (Sturge et al., 2021).

Recent research challenges the notion of the shrinking world and calls for a more nuanced perspective on out-of-home participation in dementia (Gaber et al., 2022; Odzakovic et al., 2020; Sturge et al., 2021; Ward et al., 2022). While acknowledging that dementia can restrict certain activities or places visited, these studies highlight how neighbourhoods remain important spaces of continuity, belonging, and freedom of movement (Odzakovic et al., 2020). Even when faced with difficulties such as disorientation, people with dementia develop coping strategies and continue to make decisions about their activities, thereby sustaining agency and independence (Sturge et al., 2021). Contrary to the idea of a loss of independence and control due to dementia-related impairments (Duggan et al., 2008), these findings highlight how people with dementia actively seek out opportunities for social participation and thereby retain a sense of autonomy despite the challenges they face. This capability-and strength-based view aligns with the concept of social health, which emphasises how people with dementia draw on their capabilities to balance opportunities and limitations (Dröes et al., 2017). The concept of dementia-friendly communities has gained attention as a means to enhance these opportunities by creating accessible and inclusive environments that enable participation in meaningful activities outside the home, supported by the involvement of people with dementia and caregivers, inclusive design, public education, and tailored, theory-informed strategies. (Hung et al., 2021).

Informal caregivers, often spouses, play a crucial role in supporting the social participation of people with dementia. Caregivers' own engagement in social activities can shape opportunities for the person with dementia, as they may be more inclined to involve them in activities they value themselves (Palaza et al., 2024). However, caregiving responsibilities frequently restrict caregivers' social participation and contribute to role overload (Liu et al., 2019), with dementia caregivers facing a higher risk of reduced social participation than caregivers in other contexts (Li et al., 2023). While social participation has been shown to benefit caregivers' life satisfaction (Barbosa et al., 2022), little is known about how caregivers experience changes in their own participation within the caregiving role.

Our study contributes to this growing body of literature by exploring social participation in dementia from an occupational perspective. In other words, we focus on how people with dementia experience taking part in meaningful social activities in the community, viewing this experience as dynamic and shaped by the interplay between the person, the activity, and their environment (Law et al., 1996). Given the limited knowledge about the lived experiences of social participation outside the home (Gaber et al., 2022), this study aims to gain a more nuanced understanding of how people with dementia experience their out-of-home social participation, including factors that influence these experiences. This study, therefore, explores the lived experiences of out-of-home social participation from both people with dementia and their informal caregivers, recognising the dyadic nature of participation and the interdependence of their perspectives. It is anticipated that this study will contribute to a better understanding of social participation in dementia to inform the development and enhancement of support.

## Methods

A qualitative study was conducted in the Netherlands using dyadic interviews with people with dementia and their informal caregivers to explore their experiences of social participation. The study was inspired by a critical realist perspective on language and a contextualist epistemology (Madill et al., 2000; Pilgrim, 2014). From this stance, we understood experiences of social participation as accessed through participants' accounts and interpreted by us in context. Knowledge is co-constructed through the interaction between participants and us researchers rather than discovered as a fixed truth. This perspective aligns with our reflexive approach to thematic analysis (Braun & Clarke, 2022a), wherein our perspectives and experiences were treated as an integral resource for generating insight rather than as a source of bias to be minimised.

This approach allowed us to explore the subjective experiences from people living with dementia and their informal caregivers to explore their subjective experiences through the lens of social health (Huber et al., 2011) while reflecting on how our own interpretations shaped the analysis. Additionally, the study was informed by an occupational perspective on social participation (Njelesani et al., 2014). This perspective permitted us to gain a more nuanced understanding of participants' experiences of engaging in social activities outside the home, including the influence of personal characteristics and complexities, while also accounting for contextual factors that shape these experiences.

The reporting of study findings was shaped by the tool for assessing the quality of thematic analysis research by Braun and Clarke (2021a) and The COnsolidated criteria for REporting Qualitative research (COREQ) (Tong et al., 2007). The completed COREQ checklist can be found in Appendix 1.

## Participants and recruitment

Dyads consisted of a person with dementia living in the community and a respective informal caregiver. Individuals with dementia were eligible for inclusion if they had a mild or moderate dementia diagnosis based on their Mini Mental State Examination (10–24) and/or Clinical Dementia Rating (0,5-2) scores, were living in the community, and took part in activities outside the home, with or without support. To be eligible for inclusion, informal caregivers were required to be relatives or other people closely involved in the informal care, and aged 18 or above.

Dyads were recruited between October and December 2021 using convenience sampling through staff (neuropsychologists and psychiatrists) working at the memory clinic of the Maastricht University Medical Centre (MUMC+), the case management organisation '*Hulp bij dementie*', and social media flyers. Eligible individuals were initially contacted by the first author (PH) *via* e-mail or phone. Subsequently, interested dyads were provided with a participant information sheet either by mail or e-mail. After two weeks, those still interested were scheduled for an interview appointment. Five dyads declined study participation, citing reasons such as lack of interest ($n = 3$), personal circumstances ($n = 1$), or the perception of being unable to provide a meaningful contribution ($n = 1$). There were no dropouts. All participants were given a small incentive in the form of chocolates after participation.

In total, 12 dyads were included. Participants with dementia ranged between 54 and 82 years of age ($M = 71.67$, SD = 9.54), with the majority being female ($n = 7$). Informal caregivers were aged 56–89 years ($M = 72.80$, SD = 10.18) and were predominantly male ($n = 7$). Ultimately, all included dyads consisted of a person with dementia and a person with whom they were in a committed relationship, either married or unmarried. Therefore, the term 'spouses' will be used when referring to participating informal caregivers.

## Data collection

Dyadic interviews, conducted between November 2021 and January 2022, allowed for the inclusion of a loved one to provide comfort and ease (Morgan et al., 2013) and to capture the spouse's perspective on social participation in dementia. This approach allowed both members of the caregiving dyad to reflect together on shared and individual experiences, sometimes stimulating ideas or memories that might not have surfaced otherwise, while also highlighting differences in perspective (Polak & Green, 2016). The primary focus remained on the perspective of the person living with dementia, and the interviewer actively facilitated a balanced dialogue to ensure that both voices were heard. Interviews were conducted by the first author (*anonymised*, MSc, female). PH has an educational background in occupational therapy and experience working with people with dementia. At the time of this study, she was a PhD student with prior experience and training in conducting qualitative research.

Interviews lasted between 35 and 75 min. Interviews took place at the participants' location of choice. All participants preferred being interviewed at home. Only the person with dementia, the respective spouse, and the interviewer (*anonymised*) were present during the interviews. No prior relationships existed between study participants and the interviewer. Interviews were based on a semi-structured interview guide, pilot-tested and refined with input from the European Working Group of People With Dementia (Gove et al., 2018). The guide focused on out-of-home activities, transportation, and perceived barriers and facilitators. Each topic began with a broad, open-ended question (e.g. 'What helps you to carry out these activities?'), with follow-up prompts (e.g. 'Which people support you?'). While the guide provided structure, the interviewer used additional open-ended probes (e.g. 'How does it feel to be supported?' or 'What does that connection mean to you?') to explore the deeper, subjective meaning of participants' experiences. While all key topics of the interview guide were addressed during each interview, the structure and content varied based on what the interviewer interpreted to be meaningful for each participant. Interviews were audio-recorded and transcribed verbatim. Transcripts were not returned for participant review, and no repeat interviews were performed. Field notes were taken after the interview and during data analysis.

### *Data analysis*

Data analysis was a recursive process guided by the six phases of thematic analysis by Braun and Clarke (2022b). Initially, the first author immersed in the data by listening to recordings and reading transcripts repeatedly. Subsequently, data that was relevant to address our research question was coded collaboratively by two researchers (PH and GK), aiming for richer interpretations and enhanced reflexivity. Using a predominantly inductive approach, both semantic *(i.e. descriptive)* and latent *(i.e. covering underlying meaning and assumptions)* codes were created. Interpretations and assumptions were regularly discussed to critically challenge each other's production of knowledge. Initial themes that captured patterns of shared meaning were generated and critically refined with input from the research team (LB, FV, and MdV). Writing up the results was an integral part of data analysis and led to a finalization of the themes. Participants did not provide feedback on the analysis.

Data were managed using ATLAS.ti v.22 for Mac (Scientific Software Development, GmbH, Berlin, Germany). Field notes were taken during data engagement to critically reflect on the role of the researcher in the production of knowledge. It is important to note that the conceptualisation of data saturation as a redundancy of information (Lincoln & Guba, 1985) is not theoretically coherent with our use of thematic analysis and its epistemological and ontological underpinnings (Braun & Clarke, 2021b). Instead, we conceptualise data saturation as our interpretative judgment that the analysis has sufficient depth of understanding of participants' experiences regarding their social participation. Based on this conceptualisation, data saturation was reached.

### *Ethical considerations*

The study protocol was approved by the Medical Ethics Committee of Maastricht University Medical Centre (MUMC+), the Netherlands (METC 2020–2245). All participants provided written informed consent. We used the process consent method to support people with dementia and their spouses in making an informed decision on their willingness to participate in the present study (Dewing, 2008).

## Results

From the interviews, we learned how the social out-of-home participation of study participants changed throughout the dementia. We generated the overarching theme 'Social participation: A changing world', with the following sub-themes: (1) Creating a sense of comfort and safety; (2) Pursuing a sense of social identity; (3) Accepting support to gain a sense of independence; and (4) Finding a balance: perspectives of spouses. We interpret these sub-themes as the primary strategies participants used to navigate their changing world, illustrating how they actively adapted to dementia-related changes in their social participation. The use of action verbs at the beginning of theme names reflects this agency. A visualisation of the generated themes can be found in Figure 1. An overview of the coding tree, including all themes with corresponding codes, can be found in Table 1.

### *Social participation: a changing world*

Sustaining social participation can be seen as a balancing act. Participants with dementia balance personal limitations and environmental and activity-related barriers with personal resources and environmental and activity-related opportunities. This balancing act fluctuates with dementia progression, bringing new challenges and changes that require continuous adaptation to restore balance. All participants experienced a change in social participation regarding activities, social interactions, or out-of-home mobility.

Firstly, they experienced changes in the frequency and scope of social participation activities throughout the dementia. For instance, participants reported a shift towards activities that are located within walking distance of their homes, such as walking or handling small errands. Some participants no longer engaged in certain activities, such as going on

Figure 1. Visualisation of generated themes.

**Table 1.** Overview of the coding tree.

| Overarching theme | |
|---|---|
| Social participation: A changing world | • Frequency and scope of social participation activities change<br>• Social contacts and interactions become fewer<br>• Dependency on others to get to activities increases<br>• Dementia symptoms contribute to changes in social participation<br>• Individual characteristics influence changes in social participation |
| Sub-themes | |
| Creating a sense of comfort and safety | • Activities take increasingly place in an environment that feels safe and comfortable<br>• Feeling safe in close and familiar environments<br>• Feeling comfortable in quiet environments<br>• Seeking out people who are understanding<br>• Maintaining a set routine<br>• Monitoring energy levels throughout the day |
| Pursuing a sense of social identity | • Wishing to feel treated as a human being<br>• Openly communicating about dementia<br>• Positive social encounters contribute to social identity<br>• (Keep) doing something meaningful and useful<br>• Stigma related to dementia is a barrier to social identity |
| Accepting support to maintain a sense of independence | • Value of maintaining independence<br>• Doing activities with others to maintain independence<br>• Using assistive tools to maintain independence<br>• Accepting support for out-of-home mobility<br>• Accepting that subtasks are taken over by others |
| Finding a balance: perspectives of spouses | • Encouraging attitude of spouse supports social participation<br>• Finding a balance between supporting independence of loved one and concerns<br>• Finding a balance between current and past roles |

vacation, while taking up new ones, such as attending daycare or volunteering. Secondly, several participants reported a shrinking of their social network, as friends distanced themselves following their dementia diagnosis. Additionally, the nature and extent of their social interactions evolved. Thirdly, a majority of participants felt insecure while driving or were no longer allowed to drive following a driving assessment. Consequently, they were increasingly dependent on others for their out-of-home mobility, significantly impacting both their out-of-home social participation as well as feelings of freedom and independence. In addition, it resulted in additional responsibility for spouses.

> Spouse: *'And tonight he is going for a drink with a friend. And then I'll take him, and then I'll pick him up again, too. But of course, it's not that fun. Because you've lost your freedom, haven't you? And you have to rely on everyone'.*
>
> Participant with dementia: *'Yes, it's just the way it is, isn't it? […] But that's…'*
>
> Spouse: *'Tough'.* (Person with dementia: male, 74 years old; spouse: female, 70 years old)

While dementia symptoms played an important role in influencing changes in social participation, our interviews underscored the complexity of these changes. Beyond the impact of dementia, personal factors, such as personality traits, past experiences and participants' individual histories, shaped the way they responded and adjusted to these changes. One participant who had been an active member of a local wind orchestra for most of his life continued to attend the weekly rehearsals even after he stopped playing, enjoying the music and the social connection. He also began giving saxophone lessons to his grandson, showing how his lifelong passion for music continued to shape his social participation. In addition, motivation played a role in sustaining social participation activities. Several participants continued to engage in social activities outside the home to remain physically and mentally active and to '*stimulate the brain*' (person with dementia, female, 54 years old). Others highlighted that embracing the dementia diagnosis and a positive outlook on life proved beneficial in maintaining social participation.

> *We just try to do fun things and not challenging things. Because we try to approach the positive and not the negative. That won't do you any good. […] The way I function now, that's how it is. It doesn't get better, just worse. […] You have to pluck those good moments. Later on, it will be worse, and then I might think differently. You never know.* (Person with dementia: male, 72 years old)

### *Creating a sense of comfort and safety*

Being in less familiar places, for example, during vacations, sometimes led to feelings of disorientation and distress. Consequently, participants actively sought out activities in environments that they perceived as safe and comfortable. These were mostly familiar, nearby and quiet places that formed a new zone of comfort and safety. Staying in this new comfort zone, with participants' own homes as its core, eased the balancing act of maintaining social participation. The comfort zone extended beyond the physical environment, encompassing the social environment as well. Participants with dementia created a sense of safety and comfort by actively choosing connections and interactions in which they felt safe, allowing them to express themselves freely. They appeared to find comfort in conversations marked by calmness, openness, and empathy, fostering spontaneous social engagements.

> *We do have a few people around us. One of his former colleagues, for example, we speak to him once a month. Yes, a little less now. […] Those are fun hours, and I don't have to stay up till the middle of the night. I can just say at half past ten: 'I want to go home now, I've had enough'. And that's completely fine.* (Person with dementia: female, 54 years old)

Familiarity played a central role in creating this comfort zone. Familiarity, for example in the form of well-known routes or weekly routines, enabled participants to maintain a sense of control and independence. For instance, one person with dementia mentioned the weekly visits from their grandchild. Any disruption to these weekly visits caused distress for the person with dementia. Similarly, one dyad shared their experience of visiting different campsites each year before the onset of dementia. Recognizing the undue stress for the person with dementia, they found a solution by going to the same campsite throughout the year. This solution provided a familiar environment where the person with dementia could unwind during their vacation. Another participant with dementia shared how his wife used the familiarity of the environment as a cue to facilitate his independent out-of-home mobility:

> *My wife asked me in the morning if I could go to the pharmacy to pick up medication. I didn't know how to get there. […] I say, 'I don't know where to go'. And that was a bit painful at the time. And she offered a very simple solution: "Just walk to the front door with your bike in hand. And then, see if you'll know by then". […] I looked down the street. To the left? No, that doesn't look familiar. To the right? There, I saw a familiar scene and I was helped. At that moment, I knew again which way to go to pick up the medication.* (Person with dementia: male, 74 years old)

Due to the dementia-related cognitive challenges, social participation activities, such as taking part in a conversation, were generally perceived as more tiring. Moreover, social participation in unfamiliar environments required even greater energy from participants with dementia. Consequently, participants found it essential to take periods of rest to regain balance. At times, this need for rest was accompanied by a sense of guilt, not necessarily because of expectations of others, but rather because they expected to function at a level comparable to before dementia. However, participants noted that this sense of guilt diminished over time, indicating a growing acceptance of their situation.

> *I often feel guilty when I don't do anything. I try to take more rest. Now, I don't feel guilty when I sit down on the couch later and watch television. I used to have that a lot, always had the feeling I had to do something. That has slightly lessened. But sometimes, when he [her spouse] comes back from work, I feel the 'Oh, there she is on the couch again!'. […] But I'm just tired. I'm just tired.* (Person with dementia: female, 54 years old)

## Pursuing a sense of social identity

As previously mentioned, several participants observed that their friends or even family members distanced themselves. When asked about the reasons for this, participants stated that stigma played an important role. Friends or family were afraid to ask how they were doing, did not know how to deal with the changed situation, or had limited knowledge about dementia. Stigma was particularly prominent in the social environment of younger participants with dementia, as dementia symptoms were not readily visible, and their impact often went unrecognised. To maintain a sense of social belonging, participants increasingly sought out relationships that allowed them to reinforce their social identity. This involved seeking contact with peers who shared similar experiences and could empathise with their situation, or contact with lifelong friends. Most importantly, they sought connections where they felt treated as human beings instead of feeling treated differently because of their dementia diagnosis.

> Spouse: *'You tend to back off quicker, don't you?'*
>
> Participant with dementia: *'Well, listen, […] I have noted that a lot of people find it difficult; they don't know what to say to me. Then I think, "Just treat me like a human being, I'm not a little kid after all"'* . (Person with dementia: female, 82 years old; spouse: male, 85 years old)

Participants additionally shared that certain activities, such as working, were discontinued due to dementia, resulting in the dissolution of social connections associated with these activities. This can be linked to losing a part of one's identity.

> *What I missed tremendously was that […] my work circle fell away. Fortunately, I have a work circle that still seeks contact from time to time. But I also still do very small tasks now and then, so to speak. It's not much, but you still feel you have colleagues. And that's something I miss incredibly […] I'm just way too young for that, to have nobody.* (Person with dementia: female, 54 years old)

To regain a sense of social identity, participants tried to maintain connections to previous relationships, roles, and activities that had defined their identity before the dementia diagnosis. Participants gained a sense of social identity by continuing to engage in useful activities, such as helping others at day care. Furthermore, they maintained their identity by participating in activities they had enjoyed before the diagnosis, which was facilitated by open communication. To illustrate, one participant disclosed his dementia diagnosis to his sports teammates, enabling them to provide the necessary cues during sports whenever he lost track of a conversation or was searching for words.

### *Accepting support to gain a sense of independence*

During the interviews, participants were asked about what they consider most important concerning their future social participation. Without exception, all participants expressed a wish to either continue doing enjoyable activities with others or to remain in their own homes for as long as possible. Both wishes underscore the importance participants placed on maintaining independence in their daily lives. To maintain this independence, participants acknowledged the need for coping with the changes dementia brought and accepted the need for support in certain aspects of daily life.

> *I am aware that I have a disability, so to speak. But I have to learn to live with it anyway.* (Person with dementia: male, 66 years old)

Accepting support enabled participants with dementia to continue participating in meaningful activities outside the home. One notable form of support was the active involvement of spouses. Spouses provided support in terms of transportation to out-of-home activities, for example by driving the person with dementia or by helping them to validate the train ticket before boarding the train. Additionally, spouses took responsibility for certain subtasks of activities, thereby enabling the person with dementia to remain engaged in these activities. To illustrate, one spouse mentioned being responsible for vacation planning and driving the caravan, which were previously the responsibilities of her loved one with dementia. With a shift in responsibilities, the person with dementia was able to continue going on vacation with his spouse. Moreover, by accepting their spouses' support, participants with dementia were able to regain a sense of independence. Furthermore, participants used tools and strategies to remain independent:

> *I have orientation problems too. So I still drive everywhere and I still do basically everything, but I always have a route planner on, to make sure I get where I need to go, so to speak. But also for my peace of mind, that, besides the fact that you have to pay attention to the traffic and things like that, I just have that peace of mind. That I just know with that route planner, I will get from A to B.* (Person with dementia: female, 54 years old)

### *Finding a balance: the perspectives of spouses*

This minor theme delves into the perspectives of the spouses and their role in the changing world of social participation. The majority of spouses actively encouraged their loved ones to get out and about. This encouragement involved not only assistance with transportation but also motivation to initiate social activities outside the home, particularly when dementia led to a decline in such initiatives. In most cases, spouses supported their loved ones in finding practical solutions and identifying activities that the person with dementia enjoyed doing. While most spouses were very supportive of fostering their loved ones' independent social participation, several expressed safety concerns when their loved ones went somewhere independently. These concerns sometimes posed a barrier to the person's independence, leading the spouse to accompany them out of fear that something might go wrong. In this example, one spouse mentioned driving alongside her loved one with dementia to ensure their safety on the road:

> Spouse: *'Because I would never let him go by car alone'.*
>
> Participant with dementia: *'No, I don't do that anymore'.*
>
> Spouse: *'No, he never has. I told him that. You really need to understand that. I mean, that's for both of us, isn't it? We're not waiting for anything to go wrong with the driving either, huh?'*
>
> (Person with dementia: male, 82 years old; spouse: female, 89 years old)

A delicate balance emerged between the spouse's needs in terms of their social participation and what was still possible with their partner's changing social participation. To illustrate, a couple opted for campsites closer to home, allowing the person with dementia to continue enjoying camping, even though the spouse preferred more distant destinations. Spouses also shared that they had to strike a balance between their current and past roles. Dementia not only reshaped the role of being a spouse and introduced the new role of being an informal caregiver, but it also changed other aspects of their previous roles. To illustrate this change, a spouse described a change in her role as a grandmother influenced by concerns about leaving her partner alone at night:

> *We had times when we often went to look after their children. But I went alone, and he stayed home. And I stayed overnight. But we can't do that anymore either. So those are all things that don't go so well now. But, yes. I can still get away for a day or half a day.* (Spouse: female, 68 years old)

## Discussion

This study explored the social participation experiences of people with dementia living in the community and their informal caregivers. All participants with dementia adjusted to changes in social participation by establishing physical and social comfort zones. Maintaining independence resembled a continuous balancing act between personal abilities, environmental opportunities, and barriers. For spouses, social participation similarly involved balancing their own needs with those of their loved ones with dementia. Our findings challenge the 'shrinking world' notion (Duggan et al., 2008), which associates a decrease in the frequency of out-of-home activities and the number of places visited outside the home with a loss of independence and control. Instead, they align with recent studies (Odzakovic et al., 2020; Sturge et al., 2021; Ward et al., 2022) and the concept of social health (Huber et al., 2011; Vernooij-Dassen & Jeon, 2016), highlighting the adaptive capacity of people with dementia to make choices that promote independence and foster social participation.

### Discussion of study findings

Previous studies have explored how people with dementia perceive social participation (Chaudhury et al., 2021; Donkers et al., 2019). While these studies have highlighted environmental influences, they have not recognised the agency of people with dementia in shaping their environment to support their social participation. Our findings indicate that people with dementia actively seek out connections that foster a sense of belonging and reinforce their identity within the limits they experience while distancing themselves from those associated with stigma. Simultaneously, they choose environments that provide them with a sense of comfort and safety. As such, our findings suggest that the environment is not a stable entity of obstacles or opportunities, but is dynamically shaped by people with dementia who actively select familiar places and supportive relationships that enable continued social participation. This aligns with Ward et al.'s (2022) 'lived place' perspective, viewing place as dynamically produced through engagement rather than being fixed. While there is a growing body of literature exploring this place-person relationship in the dementia context from a capability-based approach (Odzakovic et al., 2020; Ward et al., 2018; 2022), further research is needed on *how* people with dementia shape their physical and social environment to sustain social participation.

Our findings additionally indicate that family members and friends tended to distance themselves from participants, attributed to societal stigma and misunderstanding of dementia. This experience of stigma may be amplified by broader societal factors, such as negative depictions of dementia in media culture, which can reinforce social distance between people with dementia and others (Low & Purwaningrum, 2020). Similar findings were reported by van Wijngaarden et al. (2018), where disclosure of the dementia diagnosis led to people with dementia no longer being taken seriously by friends and family. Consequently, stigma emerges as a significant barrier to social participation (Burgener et al., 2015). Additionally, participants with dementia maintained connections to relationships, roles and activities that defined their identity before the dementia diagnosis, such as playing sports or having grandchildren visiting, emphasising how occupation provides continuity and a sense of normality (Strick et al., 2021). Continuity does not require identical activities but maintaining familiar routines or environments.

Our study findings show that participants with dementia placed a high value on maintaining independence, paradoxically requiring acceptance of support. Previous research indicates that people with dementia are more inclined to make adjustments that maximise their social functioning, such as accepting support (Singleton et al., 2017). Yet, they often face a tension between accepting support that enables independence and the perception that accepting support implies accepting dependency (Rapaport et al., 2020). This tension highlights that accepting support is essential for achieving the highest possible level of independence in daily life. It also prompts a critical reconsideration of the traditional concept of independence, which is often equated with self-worth (Strick et al., 2021). A shift towards viewing independence as *inter*dependence is needed in dementia care and research. From an interdependence perspective, people with dementia strive to maintain their desired level of social participation with the support of others, challenging conventional notions and fostering a more inclusive approach to social participation in dementia (Maki, 2019).

The interdependence perspective poses a complex challenge for informal caregivers, who must balance supporting independence without being overprotective, which can inadvertently disempower people with dementia and undermine their self-esteem (Rapaport et al., 2020). Spouses in our study struggled to balance their social participation needs with those of their loved ones and to reconcile current and past roles, resulting in feelings of sadness, frustration and guilt (Gallego-Alberto et al., 2022; Prunty & Foli, 2019). These findings echo evidence that caregiving demands can restrict caregivers' own engagement in valued social activities, which in turn can affect their well-being and the support they provide to the person with dementia (Wang et al. 2025). Our study adds qualitative insight into how dyads negotiate these challenges, highlighting the pivotal role caregivers play in shaping participation and the need to support both members of the dyad (Palaza et al., 2024). To provide effective support, it is essential to assist informal caregivers early in the caregiving process, enabling them to identify their needs, increase knowledge about changes in roles, and foster an awareness of the necessity for support (Boots et al., 2015). Interventions such as self-management programs for family caregivers of people with dementia have shown promise in improving caregiver self-efficacy, mastery and quality of life (Boots et al., 2018; Bruinsma et al., 2021), and may also indirectly enhance the social participation of people with dementia by strengthening caregivers' capacity and motivation to facilitate engagement.

### *Methodological considerations and clinical implications*

The strength of this study lies in its dyadic interview approach, capturing the perspectives of both people with dementia and their spouses. However, limitations need to be acknowledged. Firstly, data collection during the COVID-19 pandemic may have influenced participants' experiences of social participation (Talbot & Briggs, 2021). Secondly, study inclusion required an available informal caregiver, excluding those with limited social support and potentially greater social isolation. Furthermore, while the inclusion criteria covered a broad range of dementia stages (MMSE 10–24), most participants had milder dementia, limiting insights into differences across the dementia pathway. Future studies are needed that explore how people with dementia with limited social support and at more advanced stages of dementia adapt to changes in social participation. Thirdly, dyadic interviews may have induced response bias, with spouses potentially withholding perspectives to avoid confrontation. To mitigate this, the interviewer observed non-verbal cues to capture individual opinions. Lastly, participants seemed to be fairly active in social participation. The experiences of people with dementia who are less active may not be fully represented.

Our findings have significant implications for dementia-friendly communities and society at large. It is essential to create an inclusive environment where people with dementia can feel treated as human beings, avoid stigma, stay connected and participate in social activities that are meaningful for them. Although initiatives to reduce stigma are increasing (Devlin et al., 2007; Phillipson et al., 2019), stigma associated with dementia persists, highlighting the need for continued efforts to combat it. Designing dementia-friendly communities requires environments adaptable to individual abilities, wishes, and needs, supporting occupations that reinforce identity within familiar contexts. Rather than relying on separate activities or spaces, existing environments should be modified to enhance inclusivity for people with dementia. As examples of practical implications from our findings, the theme '*Pursuing a sense of social identity through meaningful connections*' highlights the role of social prescribers and occupational therapists in adapting past hobbies or roles (e.g. supporting continued participation in a sports team) rather than suggesting generic dementia-focused activities. Similarly, reflecting '*Finding a balance*', support groups or self-management interventions for spouses of people with dementia could include modules to help spouses negotiate role changes and balance providing support with respecting their partner's independence.

## Conclusions

The present paper aimed to explore the social participation experiences of people with dementia and their informal caregivers. Its findings indicate that people with dementia navigate a changing world of social participation, actively seeking out environments that provide a sense of comfort and safety and connections that reinforce their social identity. Acceptance of support emerged as crucial for achieving independence in social participation. Spouses, meanwhile, struggled with balancing current and past roles while aligning their social participation needs with those of their loved ones with dementia. This study challenges the notion of the 'shrinking world', underscoring the agency of people with dementia in fostering social participation and independence. Consequently, a shift is needed in research focus from the concept of a 'shrinking world' to that of a 'changing world'.

This study contributes to a more nuanced understanding of social participation in dementia and adds to a growing body of literature that approaches this from a capability-based perspective. It holds implications for the design of dementia-inclusive communities and societies by highlighting the importance of creating an environment for people with dementia which can be adapted to fit their abilities, wishes and needs. Further research is needed to explore the social participation experiences of people with limited social support and a potentially higher risk for social isolation.

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## Appendix 1. COREQ checklist

| No. Item | Guide questions/description | Reported (where?) |
|---|---|---|
| **Domain 1: Research team and reflexivity** | | |
| *Personal Characteristics* | | |
| 1. Interviewer/facilitator | Which author/s conducted the interview or focus group? | Methods: Data Collection |
| 2. Credentials | What were the researcher's credentials? E.g. PhD, MD | Methods: Data Collection |
| 3. Occupation | What was their occupation at the time of the study? | Methods: Data Collection |
| 4. Gender | Was the researcher male or female? | Methods: Data Collection |
| 5. Experience and training | What experience or training did the researcher have? | Methods: Data Collection |
| *Relationship with participants* | | |
| 6. Relationship established | Was a relationship established prior to study commencement? | Methods: Data Collection |
| 7. Participant knowledge of the interviewer | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research | Methods: Data Collection |
| 8. Interviewer characteristics | What characteristics were reported about the interviewer/ facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | Methods: Data Collection |
| *Theoretical framework* | | |
| 9. Methodological orientation and Theory | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | Methods |
| **Domain 2: study design** | | |
| *Participant selection* | | |
| 10. Sampling | How were participants selected? e.g. purposive, convenience, consecutive, snowball | Methods: Participants and Recruitment |
| 11. Method of approach | How were participants approached? e.g. face-to-face, telephone, mail, email | Methods: Participants and Recruitment |
| 12. Sample size | How many participants were in the study? | Methods: Participants and Recruitment |
| 13. Non-participation | How many people refused to participate or dropped out? Reasons? | Methods: Participants and Recruitment |
| *Setting* | | |
| 14. Setting of data collection | Where was the data collected? e.g. home, clinic, workplace | Methods: Data Collection |
| 15. Presence of non-participants | Was anyone else present besides the participants and researchers? | Methods: Data Collection |
| 16. Description of sample | What are the important characteristics of the sample? e.g. demographic data, date | Methods: Participants and Recruitment |
| *Data collection* | | |
| 17. Interview guide | Were questions, prompts, guides provided by the authors? Was it pilot tested? | Methods: Data Collection |
| 18. Repeat interviews | Were repeat interviews carried out? If yes, how many? | Methods: Data Collection |
| 19. Audio/visual recording | Did the research use audio or visual recording to collect the data? | Methods: Data Collection |
| 20. Field notes | Were field notes made during and/or after the interview or focus group? | Methods: Data Collection |
| 21. Duration | What was the duration of the interviews or focus group? | Methods: Data Collection |
| 22. Data saturation | Was data saturation discussed? | Methods: Data Analysis |
| 23. Transcripts returned | Were transcripts returned to participants for comment and/or correction? | Methods: Data Collection |
| **Domain 3: analysis and findings** | | |
| *Data analysis* | | |
| 24. Number of data coders | How many data coders coded the data? | Methods: Data Analysis |
| 25. Description of the coding tree | Did authors provide a description of the coding tree? | Table 1 |
| 26. Derivation of themes | Were themes identified in advance or derived from the data? | Methods: Data Analysis |
| 27. Software | What software, if applicable, was used to manage the data? | Methods: Data Analysis |
| 28. Participant checking | Did participants provide feedback on the findings? | Methods: Data Analysis |
| *Reporting* | | |
| 29. Quotations presented | Were participant quotations presented to illustrate the themes/ findings? Was each quotation identified? e.g. participant number | Results |
| 30. Data and findings consistent | Was there consistency between the data presented and the findings? | Results |
| 31. Clarity of major themes | Were major themes clearly presented in the findings? | Results |
| 32. Clarity of minor themes | Is there a description of diverse cases or discussion of minor themes? | Results: Finding a Balance: The Perspectives of Spouses |