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RESEARCH ARTICLE

Social connectedness and the role of virtual reality: experiences and perceptions of people living with dementia and their caregivers

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ABSTRACT

Purpose: People living with dementia are often at increased risk of becoming socially disconnected due to dementia-related challenges. In recent years, digital technology has been designed to help address the social health of people living with dementia and provide opportunities to promote or maintain their social connectedness. This paper presents the findings from phase two of a participatory action research project, which explored people living with dementia and their caregiver's experiences and perceptions of social connectedness and the potential role of Virtual Reality (VR) in promoting or maintaining same.

Materials and Methods: People living with dementia ($n=8$) and their informal caregivers ($n=8$) participated in an individual, 1:1 online interview. Data analysis was guided by reflexive thematic analysis.

Results: The findings presented four themes: social connectedness: lived experiences and insights, facilitating social connectedness, barriers to social connectedness and the potential of multi-user VR for social connectedness. People living with dementia experienced a range of personal, community and societal connectedness. Facilitators of social connectedness included supportive, non-judgemental, and reciprocal relationships, technology adoption, and personal and contextual facilitators. Dementia-related difficulties and periods of disruption or change were considered barriers to social connectedness. Multi-user VR was perceived as useful for promoting and maintaining social connectedness.

Conclusions: The perceived usefulness of multi-user VR for social connectedness indicates its potential for use with this population. Understanding the lived experiences, barriers, and facilitators of social connectedness will assist researchers and the human-computer interaction community to inform the design of future multi-user VR for social connectedness outcomes with people living with dementia and their caregivers.

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Dementia; older adults; technology; virtual reality; social connectedness; social health

➤ IMPLICATIONS FOR REHABILITATION

- People living with dementia and their caregivers consider social connectedness a vital aspect of living well with dementia.
- People living with dementia experience social connectedness across personal, community and societal domains.
- Supportive, non-judgemental or reciprocal relationships, fostering technology, and personal and contextual factors facilitate social connectedness for people living with dementia.
- Dementia-related barriers and periods of disruption and change can negatively impact the social connectedness of people living with dementia.
- People living with dementia and their caregivers consider multi-user virtual reality a promising technology to promote and maintain their social connectedness.

Introduction and background

Dementia is a term used to describe a neurological syndrome associated with various symptomatology, including progressive cognitive, functional and social health decline [1]. A progressive neurological syndrome associated with dementia is diagnosed globally every three seconds [2, 3]. Furthermore, an estimated 10-12 million people are diagnosed with dementia annually [4,5]. Being socially connected has been cited as an essential contributor to healthy ageing and is reported to guard against cognitive, physical, and mental decline, early mortality and, more specifically, dementia [6–10]. As humans, social connectedness is a prerequisite for physical and emotional survival [9–11]. Despite this, dementia-related barriers often result in people living with dementia experiencing a decline in social connectedness [12].

Van Bel, Smolders [13] define social connectedness as a brief 'experience of belonging or relatedness' between people (p.67), a definition used in other Human-Computer Interaction (HCI) research [6,14]. Social connectedness is not to be confused with loneliness or social isolation. Loneliness describes a subjective

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and affective experience of having unmet social needs, while social isolation is an objective state determined by a lack of and limited frequent social contact [14–17]. Unlike social connectedness, loneliness and social isolation describe longer-term concepts that a single social interaction cannot easily change. Despite the importance of social connectedness, people living with dementia are at increased risk of becoming socially disconnected. Difficulty holding a conversation, the stigma associated with dementia, and feeling like a burden on others are dementia-related barriers that may result in withdrawal from social opportunities, leading to feelings of social disconnectedness [18–21].

Given that there is currently no cure for dementia, psychosocial approaches to promote or maintain the social connectedness of people living with dementia and ultimately promote their social health are essential [6,22]. The past decade has seen an acceleration in technological interventions, specifically in dementia care contexts, to address social health outcomes [2,5,6,12, 22–24]. Much of the HCI community focuses on shaping and supporting older adults' social relationships and promoting social connectedness [22]. Waycott, Vetere [6] found that the use of tablet technology among the older adult community increased their social connectedness. As part of their work, they developed design guidelines for technology-based interventions for older adults that built on the dimensions of social connectedness, such as personal relationships, community connections and societal engagement [6]. Studies show that telepresence robots, such as 'Giraff' [25] and touchscreen tablets, have supported people living with dementia who reside in Residential Aged Care Facilities to stay socially connected with family members [26].

Virtual Reality (VR) is a digital technology that may foster social connectedness by facilitating shared experiences for people living with dementia [27–30]. Fully immersive VR places the user in a three-dimensional environment using a head-mounted display (HMD) and controllers to provide visual, auditory, and haptic feedback, enabling the user to interact with stimuli in the virtual environment (VE) [31,32]. VR facilitates a sense of being present in a new virtual space, distinct from one's physical environment [33]. It enables people living with dementia to escape to a novel world, encouraging participation in different activities that may no longer be accessible, such as cycling through a forest trail or revisiting past holiday destinations [28]. With fully immersive VR, people living with dementia have an experience that may be more interactive and immersive than other technologies [33]. VR can accommodate single-user or multi-user experiences. Multi-user VR enables two or more people to simultaneously be in the same VE. Most VR and dementia studies have applied single-user VR applications, or the person living with dementia used VR, while others passively interacted by viewing their interactions on a television or tablet computer screen [28].

Social VR is a subset of multi-user VR that focuses on the social aspects of interacting and engaging in VR and has recently been researched with older adults [34]. It is defined as a '3D virtual ecosystem where multiple users can socialise and interact with each other through HMDs' [35] (p.269). Social VR facilitates contact between multiple individuals in different locations without physical travel [36–39]. Some studies have explored social VR use for older adults and showed positive results, such as enriching their social connectedness with their peers, family and grandchildren [36–39] or increasing social participation [34, 40]. However, the development and use of social VR with older adults and people living with dementia remains in its infancy and warrants further exploration [28,41–43].

Furthermore, most social VR studies with older adults did not set out to focus on social connectedness but rather focused on reminiscence, social participation or engagement, with findings regarding social connectedness mainly being a by-product of the initial aims rather than social connectedness being the primary focus [36–39]. Therefore, research is needed primarily focusing on multi-user and social VR applications to promote and maintain social connectedness for people living with dementia [28,44]. To do this successfully, the needs of people living with dementia and their lived experiences of social connectedness, its barriers and facilitators must be captured and understood. VR applications, therefore, need to be co-designed from the bottom-up and informed by the experiential knowledge of people living with dementia and their caregivers [45]. As noted by Liddle, Worthy [46], understanding the 'context, experiences, needs and advice' is necessary to inform future technology for people living with dementia (p.1513). This is also an important aspect of the Participatory Action Research (PAR) process, ensuring that there is a 'real world' need for the research itself [47]. This study aims to validate the need for a multi-user VR social connecting space and understand its perceived usefulness and readiness before developing a technology that doesn't impact social connectedness or is not considered acceptable by people living with dementia and their informal caregivers [46].

This paper reports on one phase of a more comprehensive research project that employed PAR to inform the design of a multi-user, VR social connecting space for people living with dementia and their caregivers. Approximately one month before the study reported in this paper, the same people living with dementia and their caregivers experienced a fully immersive, single-user VR application [48]. This occurred in people living with dementias' respective homes and lasted approximately 25 min. It enabled people living with dementia and their caregivers to experience what it was like to be immersed in VR, pick up items, move around, and complete various tasks. Therefore, they all experienced the fundamental interactions within single-user, fully immersive VR before the current study was undertaken. The study reported in this paper aimed to:

- Explore people living with dementia and their caregivers' experiences and perceptions of social connectedness.
- Identify people living with dementia and their caregivers' perceived barriers and facilitators to social connectedness.
- Explore the potential of a multi-user VR application to promote or maintain the social connectedness of people living with dementia and their caregivers.

Materials and Methods

Study design

Participatory Action Research (PAR) is a research methodology that facilitates active participation in the design of interventions as it prioritises the views of critical stakeholders, making it more likely that the 'designed artefact' meets the needs of the end-users [49–51]. PAR involves active collaboration between the researcher and the community of interest to understand their lived experiences and perspectives of the research aims [52,53]. It consists of several cycles, namely, planning, acting, and reflecting, to achieve social change [54–57]. The number of cycles depends on each project and the needs of the community of interest, whereby the earlier phases define the trajectory of future work. Such variance in the number of cycles is reflected in other PAR studies focused on dementia [58,59]. As a research methodology, PAR helps ensure that the research process responds to the needs and priorities of people living with dementia and their caregivers. It can also help identify key areas of concern or potential opportunities for intervention or change [59–63]. The PAR research process focuses on empowering the community of interest and addressing social issues such as social disconnectedness, loneliness, and social isolation. PAR's embedded philosophy of equal power-sharing and empowerment also aligns with the wider HCI community, VR research and the objectives of this paper [49–51]. Ethical approval was obtained from the University of Galway Research Ethics Committee before the commencement of this study (reference number 2021.03.007).

Recruitment

The community of interest comprised of people living with dementia and their informal caregivers. The former were community-dwelling and residing in their homes. Recruitment was completed through purposive sampling *via* online memory cafés in Ireland (organised by The Alzheimer Society of Ireland and Engaging Dementia) and the 'TeamUp for Dementia Research' database, a national research database facilitated by the Alzheimer Society of Ireland. People living with dementia were eligible for inclusion if they self-reported a diagnosis of dementia. Initially, the inclusion criteria for people living with dementia was over 60 years of age. However, due to recruitment difficulties, this was modified to include people living with dementia who were 59 years of age (as they would turn 60 years during the project's lifetime). Recruitment of people living with dementia was contingent on the willingness of their informal caregivers to participate. Caregivers were eligible for inclusion if they were over 18 years of age. Supplementary material 1 provides further details on the inclusion and exclusion criteria.

A total of nine people living with dementia and their nine informal caregivers were initially recruited for the larger PAR project. However, one person living with dementia and their caregiver withdrew, leaving eight people living with dementia and their eight caregivers participating in this phase. Both were provided with separate participant information leaflets outlining the purpose of the research, PAR, the data collection phases, ethical and safety considerations, and a description of VR. The lead researcher used her clinical judgement as an experienced Occupational Therapist (OT) working in dementia care and the Alzheimer Society of Ireland's capacity assessment guidelines when obtaining consent [64, 65]. Informed written consent was obtained from all people living with dementia and caregivers during a previous home visit, and verbal consent was obtained before their respective online interviews. Process consent was followed throughout this phase.

Methods of data collection

Online one-to-one, semi-structured interviews were carried out with people living with dementia and their caregivers between December 2021 and January 2022. All people living with dementia and caregivers expressed a preference for online over face-to-face interviews due to the COVID-19 pandemic and the geographical distance from the university. All interviews were completed by the lead researcher (AF) using two separate interview guides. A study advisory panel consisting of two people living with dementia piloted and agreed on the interview guide before data collection commenced. People living with dementias' interview guide contained seven main topic questions and caregivers had five. In the case of short answers or responses, additional probe questions were included in each respective interview guide and were used as required (see supplementary material 2). With the consent of the people living with dementia, each caregiver was present during their interview. The caregiver's presence helped to put the person living with dementia at ease. It also enabled the caregivers to assist with any technical issues related to using the online video conferencing application- Zoom. From the outset, caregivers agreed to remain silent while the people living with dementia completed their interviews and to present their views during their own interviews. People living with dementia and their caregivers answered all topic questions. Interviews with people living with dementia ranged from 23–48 min (average 33 min), while caregiver interviews ranged from 15–32 min (average 21 min).

Data analysis

All interviews were audio recorded and transcribed verbatim by the lead researcher. NVivo 20 was used to store the data and manage the analysis process. Transcripts were reviewed by people living with dementia and their caregivers before data analysis commenced. Braun and Clarke's [66] six reflexive thematic analysis (TA) stages guided the analysis process. These stages include familiarisation, coding, initial theme generation, reviewing and developing themes, refining, defining and naming themes, and producing the report. TA's iterative and recursive nature and its emphasis on reflection complimented the key intentions of this PAR study [66,67].

AF read and re-read the interview transcripts to become familiar with the data and kept a reflexive diary to note initial patterns or ideas (stage one). Next (stage two), codes were generated from the interview transcripts using an inductive approach, creating semantic and latent codes related to the research question. Stage three consisted of organising codes into initial themes and subthemes. The unique viewpoints and experiences of people living with dementia and their caregivers were captured by completing separate analyses on both datasets from stages one to three. This meant coding and developing initial themes separately and reviewing both datasets together at stage four. Common and conflicting themes and subthemes were reviewed and subsequently merged. This process enabled the researcher to explore and report on associations and contradictions across the two cohorts [68]. It ensured that caregiver accounts amplified, not suppressed, the accounts of people living with dementia. To present a coherent report of the data, AF and AB further refined and discussed emerging themes and subthemes (stage five). These themes and subthemes were also reviewed, refined and agreed by the wider supervisory team (DC, MB, SR). Early preliminary themes were also presented to the people living with dementia and their caregivers through an informal online meeting to ensure consensus and authenticity of the findings. A detailed report of the findings (stage six) is presented in this paper, supported by primary data extracts from the transcripts to illustrate the findings further.

Trustworthiness

Trustworthiness was maintained using criteria related to dependability, credibility, transferability and confirmability [69]. Other PAR studies have also applied such criteria [70–74]. Member reflection, peer debriefing and discussion of the initial themes with people living with dementia and their caregivers were completed to ensure the credibility and confirmability of the findings. Peer debriefing with research team members confirmed the findings, whilst AF's immersion in the research area promoted credibility. Including detailed descriptions of the data collection and analysis process and supplementing the findings with direct quotations to contextualise each theme and subtheme also helped to establish credibility and transferability. NVivo 20 data management software provided an audit trail of theme derivations to aid the dependability and confirmability of the findings. Finally, the reflexive nature of PAR helped promote the study's overall trustworthiness as AF maintained a reflexive diary in NVivo using memos throughout the analysis process.

Reflexive statement

Given the reflexive nature of the analytic approach and the emphasis on reflexivity in PAR research, it is vital to understand how AF and their background shaped the analysis and interpretation of the qualitative data. AF was a PhD researcher and an OT with experience working with people living with dementia. They had experience using technology and an awareness of their bias toward its use and its benefits for social health. Given AF and DC's expertise in health and dementia care, they were mindful of the barriers and facilitators to technology design and implementation through their previous empirical work researching the psychosocial aspects of dementia and the role of technology in this landscape. They valued holistic and person-centred care approaches and were also aware of the person-environment fit, particularly the social influences impacting the daily functioning of people living with dementia. MB brought their psychology background to explore the relationship between dementia and VR use, paying attention to contextual influences. AB and SR brought their expertise in VR and games development, HCI methods and ethical aspects of technology design and implementation to interpret people living with dementia and their caregivers' experiences of VR and the casual factors influencing these experiences.

Strategies were also adopted to acknowledge and manage bias. For example, AF maintained a reflexive diary, regularly met with the supervisory team, and completed member reflection and peer debriefing meetings with people living with dementia and their caregivers.

Findings

Sample and demographics

People living with dementia and their caregivers completed separate demographic questionnaires in their own homes during the previous PAR cycle (Phase One). The lead researcher assisted in completing questionnaires where appropriate, for example, clarifying questions or verifying which checkbox to tick. The age of people living with dementia ranged from 59 to over 80 years. Each person living with dementia self-reported a formal diagnosis of dementia. Similar to other dementia research [75–78], the functional abilities of people living with dementia were classified based on the National Institute of Aging-Alzheimer's Association [75] and the Diagnostics and Statistics Manual of Mental Disorders (5th edition) stages of dementia (i.e., mild, moderate, severe) [79]. This was guided by the clinical judgement of the researcher (AF). Each person living with dementia was classified either at the mild or moderate stage of dementia with a range of 1–7+ years since experiencing initial memory difficulties. Most people living with dementia were male ($n = 6$). All caregivers were female and were related to the person living with dementia. Tables 1–3 present further demographic details, including people living with dementia and their caregivers' previous technology experience.

Table 1. Demographic characteristics of people living with living with dementia.

	People living with dementia ($n = 8$)
Age	
59–69 years	4
70–79 years	3
80+ years	1
Gender	
Male	6
Female	2
Current Support Person	
Spouse/Partner	5
Daughter	3
Length of time experiencing memory difficulties	
1-3 years	4
4-6 years	3
7+ years	1

Thematic findings

Four overarching themes were identified: social connectedness: lived experience and insights, facilitating social connectedness, barriers to social connectedness and the potential of multi-user VR for social connectedness. Subthemes were also identified within each of these themes (Table 4). To support and further illustrate the findings, additional direct quotations from people living with dementia (PwD) and their caregivers (CG) are presented in Table 5, with a more comprehensive table available in supplementary material 3.

Social connectedness: lived experiences and insights

This theme provides an insight into people living with dementia and their caregivers' lived experience of social connectedness. Two subthemes were developed, social connectedness matters: meaning and significance, and the social connectedness domains: personal, community and society.

Table 2. Demographic characteristics of the caregivers.

	Caregivers ($n = 8$)
Age	
30–39 years	1
40–49 years	1
50–59 years	4
60–69 years	2
Gender	
Male	0
Female	8
Relationship of the person living with dementia	
Spouse/Partner	5
Father	1
Mother	2
Length of time supporting a person living with dementia	
0–4 years	5
5–9 years	3

Table 3. Experience using technology.

Experience using technology	People living with dementia ($n = 8$)	Caregivers ($n = 8$)
A lot of experience (e.g., using a tablet, games console, laptop)	4	8
Some experience (e.g., using a mobile telephone)	3	0
No experience	1	0

Social connectedness matters: meaning and significance

Universally, people living with dementia and their caregivers reported that social connectedness mattered and was considered an essential component of life. Although people living with dementia and their caregivers' meaning of social connectedness varied, some key descriptions emerged: tactility, being physically present with others, and having a sense of being in regular contact with others. Several people living with dementia and their caregivers elaborated that social connectedness meant more than just talking. Others further explained that social connectedness operated in three domains: personal, community, and society. Although few people living with dementia considered the various domains to 'have equal strength' (PwD7), the majority considered personal connections with family and friends paramount. One person living with dementia reported the importance of his relationship with his siblings:

> 'Oh yeah, it [family] is everything; it is everything. If you're not connected to your nearest and dearest, you are nothing really' (PwD2)

One person living with dementia and another caregiver attributed the significance placed on being socially connected to the Irish culture's value of socialisation, whereby being sociable and supporting others was ingrained in Irish society. In particular, one spousal couple who lived rurally noted that in their small Irish community, people liked to keep up to date with one another and liked to know what was happening in their locality.

Table 4. Overview of themes and subthemes.

Themes	Subthemes
Social Connectedness: Lived experiences and Insights	Social connectedness matters: Meaning and significance The social connectedness domains: Personal, community and society
Facilitating Social Connectedness	Support, non-judgement and reciprocity Fostering technology in the digital age Personal and contextual facilitators
Barriers to Social Connectedness	Dementia-related barriers Periods of disruption and change
The potential of multi-user VR for social connectedness	Readiness for and getting acquainted with multi-user VR The appeal of multi-user VR

Table 5. Supporting quotations condensed.

Social Connectedness: Lived Experiences and Insights
Social Connectedness Matters: Meaning and Significance
'Talk comes into it [social connectedness], but also, it is about the presence. It is about meeting people. It is about reading the body language [..] It is more than just talking' (CG1)
'Just talking to a real human being and getting body language and having a laugh' (PwD9)
'Oh yeah, it is [family] everything; it is everything. If you're not connected to your nearest and dearest, you are nothing really' (PwD2)
The social connectedness domains: Personal, community and society
'Because we are on the phone with our daughter two- or three times every morning or evening. Then sometimes they ring at the end of the night to say goodnight […] So, there is lots of connectivity' (PwD7)
'With family, I feel well connected to them' (PwD6)
'He is completely cut off from everybody socially' (CG7)
Facilitating social connectedness
Support, Non-judgement and Reciprocity
'If I don't push to try and keep him connected, I can see him slipping more and more into isolation' (CG1)
'They'd [family and friends] understand it [dementia] […] they would wait for me to work it out myself' (PwD5)
'It's [keeping connected with family] a bit of both actually, you know, we both try to touch base with our children and grandchildren' (PwD7)
Fostering technology in the digital age
'I use an iPad. I don't use a computer too much now. I've got one of the smartphones and a Kindle [..] We do use FaceTime to connect to our son' (PwD1)
'He's [PwD3] got an iPhone that I don't even think can be updated anymore because it's so old. But he uses it just for phone calls and text messages [..] I'm going to get him a new phone that's bigger, and hopefully we can get used to that before your other phone dies' (CG3)
Personal and Contextual Facilitators
'[PwD5] would be a social person would have always been social and loves when people come to visit, loves when the family come' (CG5)
'We are in a very close-knit area. There's plenty of people around that are not that far away' (PwD3)
Barriers to social connectedness
Dementia-related barriers
'They are stepping back; not my friends, but my acquaintances are stepping away from me [..] I cannot cope with the information and deal with the information' (PwD3)
'I wanted to have greater participation with the [name of local club], but because I cannot get in to see them [..], it [no longer driving due to dementia] is a barrier in that respect' (PwD1)
Periods of disruption and change
'It [technology] is harder to use than it used to be [..] the technology now and then it's different' (PwD2)
'I find that one of the things that really is frustrating me [..] I'm finding it quite difficult to type properly. Now, part of it is because some of those adverts and things pop up and you're halfway through typing something and it comes up and you can't type anymore' (PwD9)
The potential of multi-user VR for social connectedness
Readiness for and getting acquainted with multi-user VR
'I could see [friends name] using it actually' (PwD1)
'For him [PwD1] I think the big thing will be keeping connected with the grandkids that are the younger generation. And I actually think his two friends would love it, they've been very supportive.' (CG1)
'It'd be nice to be able to do something that's more of like an experience together even if it was just sitting back watching a concert together [..] Having something like virtual reality to experience something together [with her mother living with dementia] would be really good' (CG9)
The appeal of multi-user VR
'I think it is a very attractive option, there is that 3D dimension to it, which you do not have on the phone, and Zoom is all verbal. It is the fact that you can see and do stuff, I think that is the most interesting part' (PwD9)
'If I was in my house and if other people were in their houses, and they were in the same virtual room. That would be interesting' (PwD6)
'Where you are interacting and sort of communicating with the other person or see the other person's point of view, empathise with the other person, anything like that is going to help keep him [PwD1] connected' (CG1)

> 'It's typical of the Irish people; they want to know the business all the time from here and there and whatever's going on. They [Irish people] keep it that way, and they know everybody, particularly in our areas' (PwD8).

One person living with dementia referenced the importance of social connectedness as it was related to his religious beliefs:

> 'It [social connectedness] is the main thing, it's in the Bible, as they tell us, 'love thy neighbour'' (PwD2)

The social connectedness domains: personal, community and society

In the main, people living with dementia were well connected to their personal connections, immediate family and friends. For all people living with dementia, having immediate and extended family members with whom they could regularly connect was vital to promote or maintain their social connectedness. Most people living with dementia maintained their social connectedness through weekly family phone calls, home visits, social occasions or celebrating family milestones. Some people living with dementia also participated in weekly meet-ups with their friends, 'solving the problems of the world!' (CG3). People living with dementia noted the importance of cherished connections with younger family networks such as children, grandchildren, nieces, and nephews. Few also reported the importance of connection to household pets.

Most caregivers discussed maintaining their social connectedness with their parent ($n=3$) or spouse ($n=5$) living with dementia. Caregivers were considered the main source of connection for their family members with dementia. One person living with dementia referenced his wife as his 'rock' (PwD2). They engaged in day trips, walks, social outings, cultural events, and watching movies together to maintain their social connectedness. One caregiver spoke about quality time spent with her mother:

> 'We go for drives or sit down and have coffee, go out to the coast, have an ice cream. So, it's just us going out, and she sees the environment' (CG5)

Another spousal couple noted that they regularly travelled together and enjoyed attending cultural events. Interestingly, this couple lived in an urban area where there may be more opportunities for attending events than those living in rural areas.

Despite experiencing personal connectedness, most people living with dementia were 'not fully connected' (PwD1) within the community domain. Some people living with dementia reported not knowing their neighbours well but being able to rely on them in an emergency. Community connectedness, although limited, was experienced through direct and indirect means. Direct means included participation in community groups such as local leisure clubs or groups. Attending local church services, dementia cafés or sporting games were also discussed. One caregiver noted that church services enabled her husband with dementia to meet others in the community, 'he actually enjoys it and talking to people outside' (CG8). One person with dementia played soccer weekly, while another attended local Irish Sporting games of 'Hurling' with his friends:

> 'We were there Sunday [.] the hurling games were brilliant and at a high standard, and it was wonderful' (PwD8).

Indirect community connectedness was experienced by people living with dementia by reading the local newspaper or newsletters, listening to local radio or watching local church services online. One caregiver discussed that her mother living with dementia engaged with the local newsletter to keep abreast with community affairs:

> 'In our local community, there is a little newsletter every week [.] she enjoys reading them and would comment on them at a time, 'such is going on'' (CG5)

Concerning societal connectedness, only a few people living with dementia experienced this. However, as previously mentioned, this was not considered the most important domain of social connectedness. Two people living with dementia reported they liked to know and 'keep in touch with what's going on' (PwD9) in the wider world. Societal connectedness was mainly experienced through engagement with social media, national and international news, and other current affairs outlets.

Although people living with dementia reported their experiences of community and societal connectedness, two caregivers did not consider the accounts given by the person living with dementia as accurate. One caregiver perceived their family member living with dementia to underestimate their means of social connection: 'She probably didn't give you all the information of what she actually does do' (CG5). Another caregiver noted that her husband over-reported, provided an inaccurate account of his social connections and considered him 'completely cut off from everybody' (CG7).

Facilitating social connectedness

When exploring the experience of social connectedness for people living with dementia and their caregivers, it became apparent that there were several facilitating factors. These are discussed under three subthemes including: support, non-judgement and reciprocity; fostering technology in the digital age; and personal and contextual factors.

Support, non-judgement and reciprocity

A few people living with dementia and their caregivers highlighted the importance of having supportive family and friends to promote or maintain their social connectedness. More commonly, caregivers referenced their role in motivating, initiating and facilitating opportunities for social connectedness. One caregiver reported:

> 'If I don't push to try and keep him connected, I can see him slipping more and more into isolation' (CG1).

Caregivers supported and initiated social connectedness by arranging calls and visits with family and the wider community, setting up technology such as Zoom, planning excursions and arranging transport.

People living with dementia and caregivers reported the importance of not being judged negatively or treated differently because of a dementia diagnosis, for example, giving time for the person living with dementia to answer questions or not asking if they remember past events. Actions such as these were seen as supportive and promoted social connectedness. One caregiver described visits from her mother's childhood friend, who was non-judgemental and understanding as:

> '…an especially joyful occasion for her [mother living with dementia], because there's no judgement. She chats, engages her, and talks about things that she can recall; if she doesn't, she will change the subject and talk about something she's familiar with. Her friend's interaction is fantastic' (CG5).

It was crucial that people living with dementia felt understood by others and that family and friends used their familiarity and knowledge of dementia to encourage interaction, engagement, and subsequent social connectedness.

Despite the need for support, some people living with dementia and their caregivers mentioned that staying socially connected worked 'both ways' (PwD3, PwD5) and required mutual give and take and reciprocity. Most people living with dementia demonstrated the importance of a reciprocal relationship where both parties are interested in maintaining their social connectedness. One person living with dementia referenced her role as a mother and grandmother who supported her grandchildren and provided her daughter with welcomed parenting advice and guidance. In parallel, her caregiving daughter supported her through the dementia journey. This, in turn, maintained their social connectedness. The same was true for a spousal couple who noted the importance of working around their son's busy schedule to stay connected with him and their grandchildren by arranging video calls around conflicting time zones.

Fostering technology in the digital age

People living with dementia and their caregivers universally considered digital technology important to promote or maintain their personal, community and societal connectedness. One person with dementia noted the positive advancements of technology for connectivity:

> 'I think it's just a general communications network that's available now that wouldn't have been available maybe even 10 or 15 years ago. Technology is the most wonderful step forward for us all and may be the saving of us all as well!' (PwD7).

One person living with dementia noted the value of video calls to make 'you feel like you are across the table' (PwD1) from family members. Interestingly, people living with dementia between the ages of 59–69 years reported greater use of technology for social connectedness compared to those in the older age ranges.

Regarding personal connectedness, people living with dementia made audio or video calls, sent and received text messages, or shared photographs/videos with family and friends on their phones. In particular, people living with dementia and their caregivers relied more on technology to facilitate social connectedness during the COVID-19 pandemic. One person living with dementia discussed transitioning from his weekly in-person catch-up with friends to Zoom during physical distancing restrictions. Being digitally literate promoted people living with dementias' connectedness to the wider community and society through the use of iPads, Kindles, Amazon Alexa, Television, YouTube and social media websites.

People living with dementias' technology adoption for social connectedness often relied on caregivers' previous technology experience. All caregivers reported having 'lots of technology' experience, which was reflected in the various technologies they adopted. Caregivers also referenced their role in supporting their family member with dementia to use technology for social connectedness, as most experienced some difficulty using technology. They highlighted the importance of introducing new, 'assistance-driven' (CG3) technology at the earlier stages of dementia to provide more opportunities for social connectedness as their dementia progressed.

Personal and contextual facilitators

Some people living with dementia and their caregivers commented on specific personal attributes and contextual factors that facilitated social connectedness. Some people living with dementia also stated that they were always open to new opportunities for social connectedness before their diagnosis of dementia, and this served as a facilitator. Most people living with dementia intentionally tried to promote or maintain their social connectedness as they were aware of their increased susceptibility to being disconnected. They and their caregivers felt a responsibility to prevent this. One person with dementia described how he motivated himself to stay connected to his friends:

> 'There are times when I'm reluctant to do it [meet friends for coffee] because, frankly, I couldn't be bothered. On the other hand, there is something in the background egging me on to keep my standards up' (PwD3)

One person living with dementia stated that her diagnosis led her to make more of an effort to be connected and not let the label of dementia 'define' her (PwD9). Another person living with dementia mirrored this, reporting:

> 'We've made a very big effort to make sure that [lack of social connection] doesn't happen. It [social connectedness] is a lifeline for all of us. We have to stay connected because otherwise, you'll just be isolated and depressed […] The last thing I would like is to sit here by myself looking at the four walls, square-eyed, from watching TV all the time' (PwD7)

People living with dementia also discussed their physical abilities as facilitators for social connectedness. One couple noted their ability to get out and walk together in their locality on weekends as a means of personal and community connectedness. Regarding contextual facilitators, half of people living with dementia and their caregivers reported the importance of having supportive communities, neighbours or living in a 'close-knit area' (PwD3). This aided social connectedness and provided a sense of place and grounding in the local community. One person with dementia reported the benefit of attending an online memory café in his local community:

> 'It [the online memory café] exposes me to other people that I have never met before [.] my range of opportunity [for social connection] is widened' (PwD7).

His caregiver reiterated:

> 'I just find that any engagement of any sort, Zoom, particularly, you know, meant that [PwD7] was seeing a different perspective on things, talking to different people, seeing different faces' (CG7).

In addition, access to cultural events, travel, online classes or reading facilitated societal connectedness. They were considered 'invisible connections to the outer world' (PwD1).

Barriers to social connectedness

However, despite the aforementioned facilitators, people living with dementia and their caregivers reported several barriers to social connectedness. These are described under two subthemes: dementia-related barriers and periods of disruption and change.

Dementia-related barriers

Caregivers highlighted that the cognitive, physical, and psychological changes attributed to dementia altered the person living with dementia's social connections with loved ones, family, friends and community. A few caregivers accepted this altered relationship once they felt people living with dementia were content. Still, most found these changes difficult, especially if there was greater social disconnectedness. One caregiver spoke about her husband with dementia being more introverted:

> 'He was never really like this before [.] he is in his own bubble, in a closed, kind of blinkered view of his world, he is happy in his world' (CG1)

Most caregivers reported that their family members living with dementia experienced reduced social connectedness on account of their dementia as they had less self-confidence in their abilities to communicate, process information or perform daily activities such as driving. Therefore, they withdrew from previous social groups. Although most caregivers reported this withdrawal and lack of social connectedness, only a subset of people living with dementia self-reported such barriers. One person with dementia reported:

> 'I'm not a very sociable person really; that's a part of me [.] I can be quiet in a group' (PwD6)

Additionally, most people living with dementia reported that they no longer drove due to dementia-related difficulties. This led to a reliance on family or friends to provide transport to attend social groups or clubs. This was particularly important for those living in rural Ireland, as there were limited public transport networks. One person with dementia in a rural area reported the impact of not driving on her ability to attend church:

> 'I always went to Mass [church], but lately, I am not able to drive [.] It blocks me out a bit' (PwD5).

Another caregiver reiterated this:

> 'Our living situation at the moment is quite isolating for [PwD7] because he doesn't drive, and we're two miles out of the town' (CG7).

Periods of disruption and change

Periods of disruption and change served as a barrier to social connectedness. Such changes and disruptions included the COVID-19 pandemic, moving house, the changing Irish culture and rapid technological developments.

Most people living with dementia and their caregivers mentioned the negative impact of the COVID-19 pandemic on social connectedness. Physical distancing restrictions impacted their ability to remain socially connected due to the closure of community groups or day centres. One person living with dementia mentioned, 'there was a lot less face-to-face' (PwD6). One caregiver noted the impact of the physical distancing restrictions on her husband's ability to meet people:

> 'We were about a year into COVID at that stage, and he wasn't really leaving the house. There was nobody coming in [to the home], obviously, because they couldn't come in!' (CG1).

Another caregiver referenced her mother with dementia's limited opportunity to meet people in her local community:

> 'We would have gone say to places that she would have people come up and say hello [.] that was gone with COVID; the opportunity to meet people' (CG5)

A few people living with dementia and caregivers referenced that the death of family and friends negatively impacted their opportunities for personal connectedness. Another couple noted that relocating from an urban to a rural location later in life decreased their opportunities for social connectedness as they did not know their neighbours. Interestingly, one person living with dementia referenced the changing Irish culture as a barrier to social connectedness. He reported that in his youth, he would attend social events such as Irish social dancing, which have since ceased, impacting his ability to meet people.

Despite using technology to stay connected, people living with dementia considered technology to be 'progressing very rapidly' (CG3). This made it difficult for them to stay abreast or use such technologies to promote or maintain social connectedness. As one's disease progressed, their use of technology also shifted. A few caregivers noted that their family members with dementia experienced difficulty with their telephones or stopped using technology such as laptops or responding to text messages as they became too complex to use or they found it difficult to type. These caregivers reported a change in their spouse or mother's technology use patterns, moving toward more passive technology, such as watching TV or YouTube instead of using their laptop or telephone to contact others. Others changed their mobile phone to a less complex model. Interestingly, all caregivers who referenced adapting to technology had 'lots of technology' experience, which may have contributed to technology adaptation as they were aware of the technology landscape.

Despite acknowledging the benefits of using digital technology to promote or maintain social connectedness, most people living with dementia and their caregivers preferred face-to-face social interactions rather than those conducted remotely. They explicitly emphasised the need to 'balance' (PwD9) technology-mediated and face-to-face connectedness. One caregiver spoke about her and her husband with dementia's transition to FaceTime to contact their grandchildren living abroad, noting its limitations.

> '20 years ago or 30 years FaceTime would not have been a thing, but at the same time, it is not a replacement for being actually present [.] giving someone a hug, it is not the same' (CG1)

The potential of multi-user VR for social connectedness

People living with dementia and their caregivers expressed a willingness to use multi-user VR in the future, including who they could use it with and its perceived benefits and appeal. It describes two subthemes: readiness for and getting acquainted with multi-user VR and the appeal of multi-user VR.

Readiness for and getting acquainted with multi-user VR

Despite not having previously used multi-user VR, most people living with dementia and their caregivers speculated on its future use to promote or maintain their social connectedness. They positively viewed the use of multi-user VR for social connectedness.

> 'It's all very promising [.] it could open up a lot of doors for people' (CG1)

> 'I think it would be absolutely superb' (PwD7)

People living with dementia and their caregivers were willing to use a multi-user VR social connecting space in the future. This may be attributed to the fact that most people living with dementia and their caregivers had at least 'some' or 'lots' of experience of using technology (see Table 3). One caregiver also referenced this and discussed her mother's love for technology:

> 'I think it's a fantastic idea. Mam always loved technology [.] I do think there is a place for that' (PwD5)

People living with dementia and caregivers expressed a willingness to use VR with one another:

> 'It would be nice to be able to do something that is more of an experience together, even if it was just sitting back watching a concert together [.] Having something like virtual reality to experience something together would be really good' (CG9)

People living with dementia were also willing to use VR to maintain intergenerational connections with grandchildren or nieces:

> 'I think the big thing will be keeping connected with the grandkids that are the younger generation' (CG1)

Outside of this personal connection, people living with dementia also expressed a willingness to use VR with friends who live at a distance or to meet new people, such as others living with dementia. A caregiver noted that her husband with dementia's 'two friends would love it' (CG1).

Although they expressed a willingness to use multi-user VR, a few people living with dementia and one caregiver requested more experiential learning. One caregiver felt that more time and testing were needed to use multi-user VR to support the social connectedness of people living with dementia. This may be because they had yet to use a multi-user VR application and were asked to speculate on future use cases. One person with a recent diagnosis of dementia noted the value of a multi-user VR application for social connectedness later in her dementia journey:

> 'I can see as time goes on, it [multi-user VR] is going to be much more important for staying connected and feeling confident' (PwD9)

The appeal of multi-user VR

The unique appeal of multi-user VR for social connectedness was apparent compared to other technologies or activities. Both people living with dementia and their caregivers considered multi-user VR as having the potential to promote or maintain the social connectedness of people living with dementia. This was attributed to it being a 'promising', 'modern', and 'fun' experience (CG1). A few people living with dementia and their caregivers referenced the unique appeal of VR compared to other technology as it provided a three-dimensional, interactive, and tactile experience to sustain engagement and promote interaction. One person living with dementia and a caregiver considered VR to provide a more immersive experience than other technologies, such as mobile phones:

> 'I think it's a very attractive option, there's that 3D dimension to it, which you don't have on the phone and Zoom is all verbal. It's the fact that you can see and do stuff, I think that's the most interesting part' (PwD9)

One person living with dementia and another caregiver noted the convenience of multi-user VR for bridging geographical distances and enabling shared social activities without the logistics of physical travel:

> 'If I was in my house and if other people were in their houses, and they were in the same virtual room. That would be interesting [..] we can be shooting lasers at each other, or we can be singing a song, or else we might be defending ourselves from other people!' (PwD6)

In addition, multi-user VR was considered a means of enabling people living with dementia to experience things that they could no longer experience due to environmental, cognitive or physical barriers. One caregiver provided an example of grandparents with dementia playing football with grandchildren in VR:

> 'Especially with much older grandparents, maybe the idea of playing football with the grandparents, they might physically not be able to do that. Whereas, doing those types of things would actually bring in things that couldn't happen in the real world with them [grandchildren]' (CG9)

Both people living with dementia and caregivers also suggested other activities that could be undertaken with one another in multi-user VR for social connectedness. These included concerts, mountaineering, music, gardening, space, sport, travel, and card or word games. In particular, travel activities were mentioned by most to enable them to visit different locations together:

> 'To find ourselves sort of near the top of Mount Everest or something like that, because we've done a lot of walking around special natural places' (PwD6)

A few people living with dementia and their caregivers also referenced multi-user VR's additional benefits, such as increased relaxation, cognitive stimulation, empathy, and gaining or maintaining confidence in social situations. Some people living with dementia and caregivers also considered multi-user VR as a potential tool to support reminiscence and a catalyst for starting conversations with others.

Discussion

This paper explored the experiences and perceptions of social connectedness, the barriers and facilitators of social connectedness and the potential role of VR in promoting or maintaining social connectedness for people living with dementia and their caregivers.

The findings revealed that the meaning of social connectedness held by all people living with dementia and their caregivers was expansive. It was described as simply being in contact with others to more complex interactions encompassing more than just talking, tactility and the physical presence of others. People living with dementia and their caregivers considered social connectedness multi-dimensional and experienced a range of social connections across personal, community and societal dimensions. Such interpretations have also been conceptualised in broader social connectedness research (from mental health domains to gerontology) [6,13,14,17]. In particular, Waycott, Vetere [6] characterised the social connectedness of older adults through personal relationships, community connection and societal engagement. Despite focusing on the general older adult population, the findings align with the people living with dementia in our study.

Previous research recognises social connectedness as essential to living well with dementia [20,80,81]. In this paper, social connectedness, particularly close personal connections with family and friends, was universally considered vital to enhance the quality of life and social wellbeing of people living with dementia. Within the personal domain, people living with dementia and their caregivers reiterated the importance of inter and intragenerational relationships with family members and friends.

Several facilitators and barriers to social connectedness were identified by people living with dementia and their caregivers. The facilitators included support from family and friends to initiate and motivate social connectedness, mutual understanding between the person living with dementia and their family members, a reciprocal relationship of mutual give and take, technology adoption and personal and contextual factors (e.g., being sociable). Support, reciprocity, and mutual understanding were also considered key to maintaining friendships in other qualitative studies involving people living with dementia, their caregivers, and friends [82,83]. The role of caregivers in facilitating and providing opportunities for people living with dementia to stay connected was also apparent. This is congruent with other dementia research where family caregivers reported feeling responsible for facilitating social networks and other identity-related activities with loved ones living with dementia, e.g., following driving cessation [80,83–85].

People living with dementia are often mistakenly perceived as 'technology-averse' or 'technophobes' who struggle to use or adopt technology, which reinforces negative ageist and dementia-related stereotypes [86]. The dementia and technology landscape refutes such assumptions, acknowledging that people living with dementia can positively adopt technology [87–89]. Our study findings also challenge this and describe the various technologies adopted by people living with dementia and their caregivers for social connectedness. It is important to consider the time point in which this research was conducted, as it was during the COVID-19 pandemic (December 2021–January 2022). People living with dementia and caregivers readily adopted technology to remain socially connected despite physical distancing restrictions during this time. This may have contributed to the range of technology adopted by people living with dementia and their caregivers for social connectedness. This is consistent with previous work, which reported that older adults [90], people living with dementia [91] and their caregivers combatted physical distancing restrictions by changing their social and technological environments. Despite initial apprehensions surrounding the adoption of new technology, people living with dementia and caregivers reported how they could use it to overcome geographical distance, reduce social isolation, connect with family, support and maintain inter and intra-generational relationships during COVID-19. This is consistent with findings from other studies [44,87,92,93].

Dementia-related difficulties and times of disruption and change were considered the main barriers to social connectedness for people living with dementia. Previous dementia research also acknowledged the negative impact of dementia-related cognitive and communication difficulties on the ability of people living with dementia to promote or maintain their social wellbeing [19–21,80].

Our study also found that rapid technological developments disrupted technology use and, thus, social connectedness. Similar sentiments were also reported by Jutai and Tuazon [90] concerning older adults and technology advancements, and they also noted that technology that is not aligned with the skills or knowledge of older adults might lead to social disconnectedness. In addition, Liddle, Worthy [46] also found that when technology is difficult to use, people living with dementia will abandon it. As highlighted by these authors, it is therefore crucial to give technological support and assistance to people with dementia so they can continue to use technology [46]. Our findings also revealed the need to balance digital and face-to-face interactions to promote or maintain social connectedness. These sentiments are shared in other related work with people living with dementia and their caregivers, particularly after the COVID-19 pandemic [20,89,94,95].

Transportation, caregiver availability and location were also considered barriers to social connectedness. Sun, Bartfay [83] also acknowledged these as barriers to engagement in their social recreational program for people living with dementia. Similar barriers to being socially connected were also experienced by the general older adult population, such as limited social spaces, not knowing neighbours well or limited availability of activities [22].

Despite the relatively novel application of multi-user VR in dementia research [42,43], people living with dementia and their caregivers were open to using the technology, which aligns with other VR and dementia studies [28,33,96]. In the context of multi-user VR for social connectedness, people living with dementia and their caregivers expressed a positive attitude towards its use [42,43]. The potential role of VR in promoting or maintaining the social connectedness of people living with dementia has also been referenced in a recent qualitative evidence synthesis, whereby VR rekindled connections with others through virtual activities [28]. A common thread in our findings was the idea of meaningful shared activities that could spark new interactions and conversations. Other research has also reported that digital technology, such as tablet applications and VR, provided opportunities for social interaction [18,24,28,32,91,97–99]. The findings in our study also acknowledged the value of multi-user VR for social connectedness as opposed to other digital technology, such as mobile phones or tablet computers, due to its immersive and three-dimensional nature. Previous studies have also acknowledged VR's potential to deliver a more immersive experience, enabling protected time away from the physical world [28,32,97].

In our study, people living with dementia and their caregivers were keen to use multi-user VR together to promote social connectedness. The importance of shared experiences between people living with dementia and their spousal caregivers to maintain their relationship was also identified in a qualitative study by Swall, Williams [100] and a VR study by Hodge, Balaam [101]. From our findings, a contributing factor to people living with dementia and their caregivers' joint enthusiasm to use VR in the future may be attributed to their use of it together. This is consistent with previous work, which reported that people living with dementia typically felt more confident in approaching and using technology if a family member or friend was present to help [87]. Some people living with dementia in our study also expressed an interest in using VR to promote or maintain intergenerational relationships with grandchildren or younger family members. This finding is consistent with a broader gerontology study undertaken by Wei, Gu [102] which explored how VR may be used to facilitate remote communication between grandparents (over 66 years) and their grandchildren and found that VR had the potential to address this through an appropriate avatar appearance, interpersonal interactions, shared activities and addressing perceived barriers to VR use. The limited multi-user VR and dementia research also supports the need for future exploration of this area to connect people living with dementia with their family members who live at a distance [42,43].

Despite a keenness to use VR for social connectedness, people living with dementia and their caregivers still had apprehensions due to the novelty of this technology. People living with dementia and caregivers in another study shared similar apprehensions relating to computer technology, namely a lack of confidence in adopting innovative technology [87]. However, despite such uncertainties surrounding the use of VR, our study found that people living with dementia and their caregivers were eager to learn more about the technology. This highlights the importance of continuously introducing and familiarising older adults, people living with dementia and their caregivers with VR, which is encouraged in other dementia and VR research [48,103].

Limitations

The COVID-19 pandemic negatively impacted recruitment and limited the participation of people living with dementia and caregivers to those with access to technology for online interviews. Interviews with people living with dementia varied in length depending on how they felt on any given day, and a flexible approach to data collection was adhered to [104,105]. Despite this limitation, adequate data was obtained to address the research aims as determined during an informal meeting, whereby people living with dementia and their caregivers discussed the findings and applied these to plan future PAR phases. Despite efforts to achieve a representative demographic, all caregivers were female, which aligned with the 'gendered nature' of dementia caregiving reported internationally [106,107]. Notwithstanding the disproportionately higher number of females living with dementia reported globally [108,109], most people living with dementia in our study were male. Thus, the findings may underrepresent the voice of females living with dementia. Although people living with dementia and their caregivers did not have experience using a multi-user VR environment before being interviewed, they all provided detailed descriptions of their perceptions of multi-user VR and its potential to promote or maintain social connectedness.

Implications for future work

This paper reports that social connectedness is vital to living well with dementia. Technology such as multi-user VR has a promising role in promoting or maintaining this area of social health and wellbeing. Nevertheless, despite the potential of VR to promote or maintain the social connectedness of people living with dementia, there is limited research detailing how to navigate the design and development process. By understanding the lived experience of social connectedness through the lens of people living with dementia and their caregivers, researchers can ascertain how multi-user VR should respond to their perceived barriers and facilitators. The findings reported in this paper are a precursor to such work and provide a clear rationale for further research exploring the role of multi-user VR in promoting and maintaining the social connectedness of people living with dementia. Although not explored in our study, future work will explore how best to design for social connectedness within multi-user VR, paying attention to avatar design, means of communication and sensitive design decisions for people living with dementia and their caregivers. Given the limitations previously mentioned, future dementia and VR research in this area should aim for a more representative and diverse sample through additional recruitment avenues outside of those employed for this research due to COVID-19 restrictions.

Conclusions

This paper explored the experiences and perceptions of people living with dementia and their caregivers concerning social connectedness and the potential role of multi-user VR to promote or maintain their social connectedness. The findings demonstrate the various domains of social connectedness and their importance for people living with dementia. People living with dementia and their caregivers reported multiple facilitators to social connectedness, including supportive, non-judgemental, and reciprocal relationships, fostering technology and other personal and contextual factors. Barriers to social connectedness included dementia-related difficulties and periods of disruption and change. People living with dementia and their caregivers were receptive to using multi-user VR to promote or maintain their social connectedness. This study served as an initial step toward understanding the lived experiences of social connectedness, the factors that support or hinder it, and the role of multi-user VR in this domain. The findings of this study establish a foundation for the future design of a multi-user VR application to promote or maintain the social connectedness of people living with dementia and their caregivers.

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Data availability statement

The data that support the findings of this study are openly available in the researcher's OSF account at https://osf.io/brdy2/?view_only=f9f920663850451192ad1db534cbde88

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