
Virtual Support Groups for People with Dementia

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Abstract

Social VR provides a variety of challenges and opportunities for people who are aging. In particular people with dementia who are at a high risk of becoming socially isolated can possibly benefit from social VR that allows them to engage with like people from home. In this paper, we discuss a preliminary social VR application that aims to supplement support groups for people with dementia using VR. Although our preliminary findings indicate that people with dementia could benefit socially and cognitively from such social VR applications, we discuss two concerns that should be addressed including accessibility and efficacy.

Author Keywords

Dementia; Alzheimer's; older adults; social support; virtual reality; support groups.

CSS Concepts

• **Human-centered computing~Human computer interaction (HCI);** *Haptic devices*; User studies; Please use the 2012 Classifiers and see this link to embed them in the text:

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Introduction

Dementia syndrome is a progressive disorder that causes memory loss, impaired cognitive ability, is often severe enough to reduce or eliminate the ability to perform everyday activities [8], and limits social engagement and interaction [16]. The most common form of dementia is Alzheimer's disease [15]. A wide variety of human-computer interaction (HCI) research has focused on people with dementia, including methods for co-designing new technologies [19,20,24] technology to assist in walking [13], and security online [23] due to high risk of attacks.

According to the American Association of Retired Persons [2], older adults want to continue to live in their current residences as well as live alone following the death of a partner as long as possible, commonly known as "aging in place." While living alone gives older adults the ability to maintain their independent lifestyles, it creates risk of these individuals developing social isolation [12,18,22]. Social isolation in turn has been correlated to poor cognitive outcomes years later[4]. For PWD, social isolation can occur due to psychological and physical barriers, low financial and resource exchange, prohibitive environments [26], and social disconnectedness [3]. Technology, such as online discussion forums, virtual support groups, and video conferencing can be used to overcome these barriers, but more research needs to be done to improve the design and accessibility of these systems for PWD.

Background

Novel information and communications technologies can provide support for PWD when designed appropriately for this population [7,27]. Specifically, research has shown that online discussion forums can foster community, promote social

interactions, and provide new ways to share and gain knowledge [9,10]. Additionally, research indicates that the enriched environments of online virtual worlds, such as Minecraft and other video games, can improve cognitive functioning [5,6].

A wide range of research indicates that improved social interaction can in turn improve health and wellbeing in elderly people with and without dementia [1,11,21,25,28,29]. At the same time, research has shown that additional exploration of the physical world improves cognitive functioning [17]. However, the ratio of caregivers to aging adults—particularly those with dementia—is rapidly shifting. This trend implies that human based caregiving must be supplemented substantially with computational support by 2050. The added challenges of mobility for this population [26] puts real-world exploration and in-person socialization at a distinct disadvantage when compared to virtual solutions.

Interactive technologies have the potential to provide an appealing and exciting experience while in the safety of one's home. These approaches also provide new therapeutic advances and enable clinicians and caregivers to monitor progress more closely. In particular, virtual reality (VR) provides engaging and dynamic experiences within enriched environments without requiring groups of elderly adults to get together in a physical therapeutic context. Even without additional interventions being laid on top of the virtual environment, the very fact that one could hold social support groups in a virtual space that feels intimate and social would dramatically cut down on costs related to therapy (e.g., leaving work as an adult child to deliver an elderly parent to therapy far away, travel time and expense related to bringing together professionals and PWD across a geographic area, and

expenses related to supplemental in-home caregivers) as well as scheduling nightmares for familial caregivers, non-profit organizations, and clinicians alike. These barriers combine to mean the most people with dementia living at home receive little to no dedicated social support. Virtual environments would provide access for those who currently have none and increase the “dosage” of social support for those in infrequent support groups. Finally, by automatically recording surrounding events, virtual systems make available a wide range of data for diagnosis, monitoring, and self-reflection not currently in existence.

Pilot Study

Social computing provides a variety of challenges and opportunities for people who are aging. In particular, following a recent diagnosis of dementia, older adults sometimes engage in online communities designated for people with dementia. To begin to understand these practices, we conducted a qualitative analysis of posts to an online discussion forum for people with dementia [14]. We used a web scraper to gather original posts from an online forum specifically created for people with dementia to interact and discuss a variety of issues and subjects. Once posts were gathered, we coded the data to understand the types of social support that represented by these posts. We not only found that PWD seek or provide various types of social support including informational support, emotional support, and companionship (network support), but we also found that these individuals are not the only people interacting on the forum. Our findings indicated that in addition to newly diagnosed people with dementia (the ostensible target of the forum), people who are pre-diagnosis, family members, caregivers, “dementia trailblazers,” and people without

dementia all interact in this forum and provide varying types of social support.

We have begun a long-term qualitative field study in partnership with a local Alzheimer’s support organization. This group provides educational programs, family training, 24/7 helpline, memory screenings, and support groups for families and individuals living with Alzheimer’s and other types of dementia across three adjacent and highly populated counties in four languages. Although this work is in its early stages, early results indicate that both caregivers and PWD experience social isolation. This isolation is greater when English is not the primary language, they live far from a primary support center, and there is a mix of working and not working in the families. Due to these challenges will conduct interviews with these individuals to understand their perspectives on technology and what makes support groups important for to them. The goal of these interviews is to get a preliminary understanding of how virtual reality support groups can be used to supplement face to face support groups or even allow individuals who are unable to attend support in person experience the impact of support groups virtually.

Discussion

The potential use cases for eldercare via VR are substantial, but in this work we are focused on the concerns around social isolation and subsequent cognitive and emotional challenges related to that isolation. VR can help supplement support groups and create access to support groups for people with dementia and their caregivers given appropriate design and implementation within the social VR space. To understand how to design social VR environments, such as support groups for people with dementia, we must

consider two primary concerns: 1) how can the virtual support groups mimic the experience of face to face support groups and 2) what does accessibility for older adults look like in social VR.

Social VR is an appealing approach for supplementing or replacing in person support groups, because they provide an immersive experience that can be cognitively supportive [5,6] as well as entertaining. Our preliminary results indicate that feeling like elders are with others and interacting socially is an important component to in person social support groups that are not mimicked with current online communities. Social VR has the potential to address this need. However, for this population the exact implementation to mimic face to face without creating a confusing or disconcerting experience will have to be explored carefully. For instance, using 360 video that engages the participant in conversation by name can be a way to mimic such experiences in a modality that is familiar: video. At the same time, virtual instantiations of support group participants through non photo-realistic approaches, such as cartoon avatars, may limit elder confusion or the experience of the “uncanny valley” that can emerge in photo-realistic VR experiences. We are currently planning additional trials to test these modalities.

Beyond the creation of efficacious and engaging software experiences, social VR for elders with dementia requires a broad consideration of accessibility in both the hardware and software. Accessibility requirements for this population require consideration of navigation within the software, adjustment and personalization of audio and video cues, and enabling VR features to be customizable by caregivers to optimize the experience of their loved ones. Likewise, the physical kit (e.g., VR headsets, headphones, microphones) must be suitable for wearing by people

with thin or brittle skin, weakened head and neck muscles, and who may use mobility supports.

Conclusion

People with dementia are at a high risk of becoming socially isolated due to social disconnection and lack of mobility. Current best practices call for use of in-person social support groups. However, these are often far away, require substantial effort to attend, and are rarely offered more than once per week. Older adults with dementia could benefit from social virtual support groups, which will allow them to be able to have immersive support group experiences and build connections with people who are in similar situations on a more frequent basis at a lower cost. To achieve this, researchers must begin to understand how virtual support groups can mimic the experiences of in person support groups and understand the accessibility requirements related to social VR and older adults with dementia.

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References

- [1] Sato Ashida and Catherine A. Heaney. 2008. Differential Associations of Social Support and Social Connectedness With Structural Features of Social Networks and the Health Status of Older Adults. *Journal of Aging and Health* 20, 7: 872–893.

- [2] Linda Barrett. 2015. *Home and Community Preferences of the 45+ Population 2014*. AARP Research.
- [3] Shari S. Bassuk, Thomas A. Glass, and Lisa F. Berkman. 1999. Social Disengagement and Incident Cognitive Decline in Community-Dwelling Elderly Persons. *Annals of Internal Medicine* 131, 3: 165.
- [4] John T Cacioppo and Stephanie Cacioppo. 2014. Older adults reporting social isolation or loneliness show poorer cognitive function 4 years later. *Evidence Based Nursing* 17, 2: 59–60.
- [5] G. D. Clemenson and C. E. L. Stark. 2015. Virtual Environmental Enrichment through Video Games Improves Hippocampal-Associated Memory. *Journal of Neuroscience* 35, 49: 16116–16125.
- [6] Gregory D. Clemenson, Shauna M. Stark, Samantha M. Rutledge, and Craig E.L. Stark. 2019. *Enriching hippocampal memory function in older adults through video games*. Neuroscience.
- [7] Maria Manuela Cruz-Cunha, Isabel Maria Miranda, and Patricia Gonçalves, eds. 2013. *Handbook of Research on ICTs and Management Systems for Improving Efficiency in Healthcare and Social Care*: IGI Global.
- [8] Tom Dening and Malarvizhi Babu Sandilyan. 2015. Dementia: definitions and types. *Nursing Standard* 29, 37: 37–42.
- [9] Bette Gray. Informal learning in an online community of practice. *Journal of Distance Education*: 20–35.
- [10] Darja Groselj. 2014. A webometric analysis of online health information: sponsorship, platform type and link structures. *Online Information Review* 38, 2: 209–231.
- [11] Norfazlina Haris, Rogayah A. Majid, Natrah Abdullah, and Rozianawaty Osman. 2014. The role of social media in supporting elderly quality daily life. *2014 3rd International Conference on User Science and Engineering (i-USEr)*, IEEE, 253–257.
- [12] Jörg W. Haslbeck, Ruth McCorkle, and Doris Schaeffer. 2012. *Chronic Illness Self-Management While Living Alone in Later Life: A Systematic Integrative Review*. *Research on Aging* 34, 5: 507–547.
- [13] Kristine Holbø, Silje Bøthun, and Yngve Dahl. 2013. Safe walking technology for people with dementia: what do they want? *Proceedings of the 15th International ACM SIGACCESS Conference on Computers and Accessibility - ASSETS '13*, ACM Press, 1–8.
- [14] Jazette Johnson, Rebecca W. Black, and Gillian R. Hayes. Roles in the Discussion: An Analysis of Social Support in an Online Forum for People with Dementia. *ACM Conference on Computer Supported Cooperative Work and Social Computing*. Under review.
- [15] Stella Karantzoulis and James E Galvin. 2011. Distinguishing Alzheimer's disease from other major forms of dementia. *Expert Review of Neurotherapeutics* 11, 11: 1579–1591.
- [16] Mary F Kelley. 1997. SOCIAL INTERACTION AMONG PEOPLE WITH DEMENTIA. *Journal of Gerontological Nursing* 23, 4: 16–20.
- [17] Brandon S. Kolarik, Shauna M. Stark, Samantha M. Rutledge, and Craig E.L. Stark. 2019. *Enriching hippocampal memory function in older adults through real-world exploration*. Neuroscience.
- [18] Ashish Kumar, Maode Ma, Chiew Tong Lau, and Syin Chan. 2017. A Framework of Real-time Wandering Management for Person with Dementia. *Proceedings of the 8th International Conference on Computer Modeling and Simulation - ICCMS '17*, ACM Press, 146–150.
- [19] Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. A Critical Lens on Dementia and Design in HCI. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI '17*, ACM Press, 2175–2188.
- [20] Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. Supporting People with Dementia in Digital Social Sharing. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI '17*, ACM Press, 2149–2162.
- [21] Phuong Leung, Martin Orrell, and Vasiliki Orgeta. 2015. Social support group interventions in people with dementia and mild cognitive impairment: a systematic review of the literature: Social support

groups in dementia. *International Journal of Geriatric Psychiatry* 30, 1: 1–9.

- [22] Roisin McNaney, John Vines, Jamie Mercer, Leon Mexter, Daniel Welsh, and Tony Young. 2017. DemYouth: Co-Designing and Enacting Tools to Support Young People's Engagement with People with Dementia. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI '17*, ACM Press, 1313–1325.
- [23] Helena M. Mentis, Galina Madjaroff, and Aaron K. Massey. 2019. Upside and Downside Risk in Online Security for Older Adults with Mild Cognitive Impairment. *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems - CHI '19*, ACM Press, 1–13.
- [24] Timothy Neate, Aikaterini Bourazeri, Abi Roper, Simone Stumpf, and Stephanie Wilson. 2019. Co-Created Personas: Engaging and Empowering Users with Diverse Needs Within the Design Process. *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems - CHI '19*, ACM Press, 1–12.
- [25] Jason T. Newsom and Richard Schulz. 1996. Social support as a mediator in the relation between functional status and quality of life in older adults. *Psychology and Aging* 11, 1: 34–44.
- [26] Nicholas R. Nicholson Jr. 2009. Social isolation in older adults: an evolutionary concept analysis. *Journal of Advanced Nursing* 65, 6: 1342–1352.
- [27] Gabriela Postolache, Raul Oliveira, Pedro Silva Girao, Miguel Dias Pereira, and Octavian Postolache. 2017. Tailoring information and communication technologies to support physiotherapy for rural elderly. *2017 E-Health and Bioengineering Conference (EHB)*, IEEE, 93–96.
- [28] Kevin Wright. 2000. Computer-Mediated Social Support, Older Adults, and Coping. *Journal of Communication* 50, 3: 100–118.
- [29] Ruby Yu, Elsie Hui, Jenny Lee, et al. 2015. Use of a Therapeutic, Socially Assistive Pet Robot (PARO) in Improving Mood and Stimulating Social Interaction and Communication for People With Dementia: Study Protocol for a Randomized Controlled Trial. *JMIR Research Protocols* 4, 2: e45.