Virtual Support Groups for People with Dementia

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;

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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 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**


