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Virtually supportive: A feasibility pilot study of an online support group for dementia caregivers in a 3D virtual environment

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Abstract

Caregiver support groups effectively reduce stress from caring for someone with dementia. These same demands can prevent participation in a group. The present feasibility study investigated a virtual online caregiver support group to bring the support group into the home. While online groups have been shown to be helpful, submissions to a message board (vs. live conversation) can feel impersonal. By using avatars, participants interacted via real-time chat in a virtual environment in an 8-week support group. Data indicated lower levels of perceived stress, depression and loneliness across participants. Importantly, satisfaction reports also indicate that caregivers overcame the barriers to participation, and had a strong sense of the group's presence. This study provides the framework for an accessible and low cost online support group for a dementia caregiver. The study demonstrates the feasibility of interactive group in a virtual environment for engaging members in meaningful interaction.

Keywords

Support group; Web-Based; Virtual World; Avatar; Dementia; Caregiver; Internet

Thousands of Americans provide care for a friend or loved one with dementia, with the majority of care coming from family members in the home. Caregiving is increasing as rates of dementia increase and as the population ages. The impact of caregiving for a person with dementia is not trivial; US businesses lose \$17.1 to \$33 billion per year, due to lost productivity and replacement costs of family caregivers (*MetLife Study of Working Caregivers and Employer Health Costs.*, 2010). In a longitudinal cohort study of almost 400 older spousal caregivers, caregivers who experienced mental or emotional strain related to caregiving had 63% higher mortality risk than low-stress caregivers and noncaregiving controls (Schulz & Beach, 1999). The repercussions of caregiving include personal, social and health costs (Schulz, Martire, & Klinger, 2005). Caregivers experience high rates of depression, poor physical health, and social isolation.

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Multiple recent studies have demonstrated the impact of caregiving and the clinical utility of intervention for reducing the negative impact of caregiving, and likewise demonstrate increases in caregiver self-efficacy and confidence. An array of reviews and meta-analytic studies reviewing this body of research has emerged. In a recent meta-analysis, Pinquart and Sörensen (2011) analyzed the impact of caregiving on three different groups: spouses, adult children, and children-in-law. Results indicate that due to significantly higher levels of care provision, spouses experience differentially more depressive symptoms, physical and financial burden, and lower levels of psychological well-being. However, adult children of the care recipient reported the highest incidence of stressors from caregiving, suggesting that although they report fewer depressive symptoms, children of care recipients still experience significant caregiving stress. Importantly, the authors conclude that both groups may benefit from intervention in different ways. Spouses may benefit from reduction in caregiving demands (e.g., respite, more effective care provision) while children may benefit from a relationship strengthening approach (e.g., better communication, increased pleasant activities experienced with care recipient). The present study employs an intervention program that highlights both areas, as it emphasizes the importance of pleasant activities, communication skills, and increases positive coping skills to reduce burden.

In another meta-analytic investigation, Chien and colleagues (2011) investigated the impact of support groups on various measures of well-being in non-professional caregivers of dementia patients. Thirty empirical research articles from 1998–2009 were included and measures of psychological well-being, depression, burden, and social outcomes were assessed. Effect sizes (i.e., Hedge's G) for all four measures were significant, indicating that participation in a support group led to improvement on each of these measures. Interestingly, those support groups that were manualized and with a duration of 8 weeks had the strongest effect sizes and showed significant improvement in each of the four areas assessed. The current study employs a support group design with both of these qualities.

Caregiver support activities, including support groups, have shown benefits to the caregivers' mental health (Schulz et al., 2007). As Brodaty and colleagues demonstrate in a meta-analysis (2003), psychosocial interventions for caregivers of individuals with dementia can lead to important benefits, including reduced burden, reduced anxiety, and increased overall psychosocial well-being. Support group research has now focused more closely on elucidating the components of a support group that are the most effective (i.e., beneficial and efficient) as well as identifying ways in which support can be most effectively given and widely disseminated. Both involve efforts towards a goal of identifying and reaching more caregivers in need of support, and providing the most effective support to those individuals. In a recent study, Judge and colleagues (2013) investigated the benefits of a support group, highlighting some of these effective components: educational skills, effective communication, staying active, and recognizing emotions and behaviors. Compared to controls, those caregivers receiving this intervention, entitled "Acquiring New Skills While Enhancing Remaining Strengths" (ANSWERS), exhibited lower emotional-health strain, fewer symptoms of depression and anxiety, and higher caregiving mastery (e.g., confident decision-making). In sum, strain was reduced based on a support group that highlights key components of intervention. Continued research investigating how support group intervention might parsimoniously target these key domains of support is still emerging.

However, support groups have significant barriers to participation and new modes of technology may overcome these barriers. Caregiver support groups can be effective, but new models of deployment, including the use of technology, should be considered. A range of Internet-supported interventions has been developed for caregivers, most notably the Alzheimer's Association (<https://www.alzconnected.org/>). Research has investigated the use of online support groups for caregivers (Perron, 2002; Pierce, Steiner, & Govoni, 2002). Boots and colleagues (2013) provide a current systematic review of these. They include a combination of informational websites, with some additionally including telephone or email support, or exchange with other caregivers online. Evaluations of Internet-based support interventions for caregivers with dementia have shown that caregiver confidence, depression, and self-efficacy improve as a result of intervention. Hayden and colleagues (2012) recently reviewed the benefits of online education, support and self-care promotion from a large randomized trial. Despite some difficulties, results of available research indicate that participants usually find the online technology beneficial because a) the material is enjoyable, b) in-home access is convenient and c) they receive online support from professionals and other caregivers.

Two barriers to caregiver support groups are: (a) required travel (to the support group location), and (b) caregiving duties. Brodaty and colleagues (2005) identify some of the common barriers to service use in caregivers of dementia patients. They include a care recipient being too impaired, which prevents caregivers from being able to get to support groups, and being too busy to use services. Additionally, stigma associated with dementia leads to isolation. Morgan and colleagues (2011) developed a support group designed to accommodate those in rural areas, and found similar barriers. They used focus group data to identify the possible barriers preventing caregivers from using formal services. They concluded that barriers were: (a) privacy and anonymity: related to stigma, being able to maintain privacy about the patient and requisite caregiving activities would likely lead to more caregivers utilizing groups, home care assistance, etc., (b) geographic limitations: living in rural communities or having few transportation options can restrict opportunities for in-person support and for access to health professionals, (c) service provision challenges: dementia patients might not want or think they need help, making the job of a caregiver very challenging. Access to informational support groups and assisted in-home care allows the caregiver to stay with the patient while also learning how to overcome obstacles.

The present study innovatively overcomes these barriers through the use of technology. First, caregiving duties frequently interfere with a caregiver's ability to attend a support group. This impediment to participation can be addressed through online communication, allowing the caregiver to remain at home while participating in the support group. Using the Internet allows people to communicate in groups in real time without requiring them to be in the same location.

Second, an innovation of technology is the use of virtual worlds on the Internet, where participants are visually represented (with an avatar), and are able to see other members of the group represented as avatars. One advantage of avatars is that they mimic face-to-face interaction. Much of human communication takes place nonverbally, through facial expression, embodied movement and dynamic group interactions (for a review, see Knapp

& Hall, 2009) and the use of avatars affords some of these nonverbal aspects. Although other forms of online communication (e.g., message boards, email) provide the content necessary to experience support from a group, avatar embodiment may provide an additional route to the emotional experience of support that could reduce loneliness and social isolation.

Coping With Caregiving (CWC) is an evidence-based treatment developed with the extant supportive evidence for the therapeutic effects of psychoeducation and skill training (Gallagher-Thompson & Coon, 2007). This intervention condition is rooted in cognitive behavioral practice, focusing largely on psychoeducation to teach coping and mood management skills. Specific findings from the CWC implementation include a significant reduction in depressive symptoms and a significant increase in positive coping strategies when compared to a typical community-based support group (Gallagher-Thompson et al., 2003), although both groups were effective in reducing perceived caregiver burden compared to baseline. CWC was one component the Resources for Enhancing Alzheimer's Caregiver Health (REACH) studies (Belle et al., 2006). We chose to utilize portions of the protocol that were amenable for adaptation to a brief, online support group intervention.

In summary, the present study investigated the feasibility of using online virtual support groups for caregivers of persons with dementia, assessing subjective reports of burden and negative affect and querying the participants as to the utility of the groups.

Methods

Participants and recruiting methods

All participants were recruited from the greater Tucson and outlying regions. Seven of the original ten participants completed the study. Participants were recruited through the community and local university and university hospital campus. Informational and advertisement fliers and emails were delivered to relevant campus organizations as well local community outlets, including the local paper, the local Area Agency on Aging, and area geriatricians. Collaboration with a local retirement community provided another recruitment opportunity.

Enrollment and technology

All potential participants who telephoned for information about the study were given further details regarding the nature of the research, the goals of the intervention, and the time commitment of participation by the project coordinator (B.A.). As part of the inclusion requirements, all participants were caring for an immediate family member who had a diagnosed age-related dementia. All participants had in-home access to a working computer with Internet service already established. During the phone interview, caregivers described their personal caregiving situation, including type and duration of diagnosis of their loved one. Additionally, participants were administered the Braztel Mini-Mental State Exam (Camozzato, Kochhann, Godinho, Costa, & Chaves, 2011) to document cognitive functioning of the caregiver. All participants in this pilot study provided informed consent via procedures approved by the University of Arizona Human Subjects Protection Program.

The virtual reality (VR) support group was conducted using the software program Second Life (SL, Linden Research, Inc.¹). The Second Life platform is a program offering rich visual and interactive 3 dimensional features, wherein a user selects their own character or “avatar” and is able to navigate through the virtual world using simple keyboard commands. For consistency across different types of home computers and web browsers, communication was limited to typed text.

Groups were kept small ($n = 3-4$) because we predicted that the groups would be smoother if there were fewer technical difficulties to overcome (due to a smaller number of group members). We also wanted to ensure that each person would have more time to talk with a small number of members, given that the rate of talking through texting might have taken longer due to the novelty of this method.

The virtual environment was a private living room setting, accessible only by those in the VR support group. Caregivers were given instructions over the phone for login and communication along with additional written instructions for choosing from a list of available avatars (Figure 1) and navigating through the virtual environment. Navigation included learning to walk, open doors, and sit on the provided chairs in the cozy log cabin where the group met (Figure 2). Each participant was given time to practice logging in, navigating in the environment, and conversing with the study coordinator in the Second Life virtual environment prior to the first session. To protect participant identity, each was given a non-identifying username and password to log in during their assigned group.

Psychosocial measures

Psychosocial data was collected in a pre-/post-intervention design. Pre- and post-intervention measures included the UCLA Loneliness Scale (Russell, Peplau, & Cutrona, 1980), the Geriatric Depression Scale (Sheikh & Yesavage, 1986), the Zarit Burden Interview (Bédard et al., 2001), and the Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983). The post-intervention survey was completed one week after the final group session. Additionally, participants were prompted to provide anecdotal comments about their experience to elicit free-response feedback about the utility and effectiveness of the online group. This project used an intra-case analysis. Because the quantity of data was quite small ($N=7$) and constrained by evaluative questions, all of the qualitative responses were read simultaneously. After reading the responses, the frequency with which different issues arose was noted. Because of the small number of responses, every participant was reflected in the reported qualitative data, with representative quotes chosen from the comments.

Group intervention model

Each group convened weekly for one hour, for eight weeks, and included a psychologist (M-F.O.) and a project coordinator (a clinical psychology graduate student; B.A.). One group had three caregivers and one group had four caregivers. The psychologist facilitated each session. With some variation, each of the eight sessions drew psychoeducational information

¹Several version updates were made to Second Life during the course of the study, and the latest version was 3.6.4.280048.

from didactic modules in the manual *Coping with Caregiving: Reducing Stress and Improving Your Quality of Life*, v2 (Gallagher-Thompson et al., 2002). These topics included changing difficult behaviors, changing unhelpful thoughts, communication styles, communication and memory problems, planning for the future, and pleasant events. Groups were driven primarily by participant discussion, with some direction and information provided by the psychologist.

Results

Ten participants originally signed up for the support groups, and seven participants completed them. Reasons given for non-completion were being too busy (n=2) and technical difficulties (n=1). Using Fishers exact test, there were no significant differences between completers and non-completers in sex, length of time since dementia diagnosis, ethnicity, age, whether they had been in another form of therapy, drinks per week, smoker status, education or employment status. Demographic data for the completers is shown in Table 1.

In all of the self-report variables, completers' status improved after the support group (Figure 3). In a repeated measures ANOVA, only the Perceived Stress Scale approached significance ($F = 3.67$, $p < 0.1$); however, the partial η^2 was .42. Mean changes were in the expected direction of improvement, but power was insufficient in this feasibility pilot study for these differences to reach statistical significance.

When asked, "What was the best part about the group for you?" responses fell into two categories. First, participants commented on specific techniques and tools they learned from the researchers (e.g., "The little tips to try during the week", and "I learned about eldercare legal issues"). Second, participants commented on general supportiveness of the group (e.g., "Hearing from others who have similar experiences", and "Knowing my family and I are not alone in what we're facing").

When asked, "What did you wish was different or would you like to see changed about the group?" responses varied. Some reported they could not think of any improvements. One reported "More time in the beginning to learn how to move my avatar". One participant explained that she wished the groups had only been spouses or daughters of dementia patients, but not both because the issues are somewhat different. Two group members wished the groups were bigger.

Some wished for more time or resources, with creative ideas about how to achieve this:

[I] needed more time to talk about issues with others in the group. I felt we didn't have enough time to post all of our thoughts on a subject before [the psychologist] would lead us to a new topic of discussion. I would have liked to have met several times a week.

I would like a component in which questions or concerns could be posed and then members had the week to respond and share thoughts. The on-line chat didn't allow for that.

Responses to questions regarding satisfaction with the intervention can be found in Table 2. When asked, "Do you prefer to meet online or going to a meeting in person?" several people indicated that they preferred the online meetings because they did not have time to go out to a group (especially for those who were still working), but that they recognized how helpful the group was. However, they also indicated that they liked having someone to moderate the group.

Discussion

In the present feasibility pilot study of virtual online support groups for caregivers of dementia patients, questionnaire data and participant feedback suggest that virtual online support groups are feasible for older adults and that they may potentially be effective. This small pilot study of caregivers had few participants; however, loneliness, depression, perceived stress and caregiver burden all were nominally lower after the eight-week intervention, although only perceived stress approached significance. For depression, this may, in part, be because the levels were so low at the beginning of the intervention. Reducing caregiving burden was the primary focus of the groups, and the measure of this domain did show nominal improvement. The online support groups appeared to overcome the participation barrier as expected: those who did not want to leave their home were able to participate in a support group, and reported benefits. Notably, the caregivers reported that they experienced being in the room with the other caregivers, even though they never met in person.

Given the growing number of caregivers for adults with dementia, and the evidence that specific support group interventions are effective at reducing mental health problems, and improving psychological well-being (Pinquart & Sörensen, 2011), the present study adds a novel method for administering these support group interventions. The present results (albeit from a small sample) suggest that virtual online support groups have the potential, if supported by data from future randomized controlled evaluations with larger samples, to improve mental health for dementia caregivers.

Although research has determined that it is effective for reducing caregiver isolation and burden (Boots et al., 2013), the mechanisms by which these interventions are effective must be determined (Lavretsky, 2005). The present project encourages testing of the hypothesis that the embodied (albeit virtual) experience of being present in a room in real time (i.e., synchronous) with other caregivers may be an important ingredient in the effectiveness of the intervention. Future research should compare the use of avatars with other text-based (i.e., non-avatar) or asynchronous (i.e., message board, email) support groups.

Why use avatars as opposed to video interactions? With the advent of software like Skype, it is possible for participants to see and hear each other in real time. There are two reasons that this medium was not used for the present study. First, we learned from the caregivers' feedback that some anonymity is often preferred. This allows the caregivers to join the group even when they have a busy day, and may not have had a chance to shower or clean up their house in the way they would prefer for another video viewer. In addition, they may

feel freer to disclose difficult experiences and emotions (e.g., frustration, anger) knowing that their identity and privacy is protected.

There is a second reason not to use audio-video conferencing. The technical requirements of audio-video conferencing are greater than for the present virtual group. This means fewer older adults could participate since the study relied on the use of the individual's own home computer. In our experience, almost all computers were able to utilize the text- and graphic-based program here employed, but many home computers would not have a webcam and audio capabilities for audio-video conferencing. In fact, subsequent to the present study, text-based Second Life (as we used) can now be used with an Android operating system, allowing it to be accessed from an Android tablet.

While offering advantages such as an approximated real world experience, use of virtual reality is not without limitations. In the course of this project, several obstacles arose. The first involved connectivity, wherein one potential participant was unable to run the program due to inadequate computing equipment, thus preventing her from participating. Beyond screening for this information during intake, one possible workaround is to temporarily provide the participant an adequate computer for the duration of the group. An additional obstacle involved program download. During the download process, one participant followed a misleading web link, resulting in the installation of malicious software. Providing trouble-shooting advice and a professional malware removal resolved this situation. However, this occurrence emphasizes the need for explicit and easy-to-follow instructions, for security protection, and for live technical support from project personnel.

In conclusion, the use of avatars in an online support group for dementia caregivers appeared both feasible and potentially effective in the present pilot study. We look forward to future, more rigorous evaluations, and, pending results of such evaluations, to the increased use of this medium to reach isolated and geographically distributed dementia caregivers.

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Appendix A. Session one excerpt

The following excerpt is an example of one element of skill building employed during the support group.

[19:15] Psychologist: Caregiving is hard on us physically and breathing slowly can help us both psychologically and physically.

[19:15] Psychologist: Have any of you ever done any yoga, or meditation, or anything?

[19:15] Caregiver 2: Yes.

[19:16] Caregiver 3: I've tried yoga at the gym I go to. It is relaxing

[19:16] Psychologist: Relaxing is the idea, for sure

[19:16] Psychologist: So, instead of doing a whole class or becoming a guru, we're just talking about taking a few minutes

[19:16] Psychologist: Would you be willing to give it a try now with me, if I give you some ideas?

[19:17] Caregiver 2: yes

[19:17] Caregiver 1: sure

[19:17] Psychologist: There are two main ideas

[19:17] Psychologist: First, letting your belly get bigger as you inhale

[19:17] Psychologist: and second, exhaling for longer than you inhale

[19:17] Psychologist: you can count if you want, or just pay attention

[19:17] Psychologist: Let's do this for a minute or two, and see how we feel

...

[19:18] Psychologist: How do you feel?

[19:18] Graduate student: I always enjoy this

[19:19] Caregiver 2: soothed.

[19:19] Caregiver 1: easier to think again

[19:19] Psychologist: yeah

[19:19] Caregiver 3: that was calming

[19:19] Psychologist: I'm always surprised, because I didn't know I felt stressed

[19:19] Psychologist: So, I wonder if we could try to do this this week? It only is a couple of minutes, but it can be soothing. What do you think?

[19:20] Caregiver 1: ok here

[19:20] Caregiver 2: yes.

[19:20] Graduate student: I will be as well

[19:20] Caregiver 3: I'm in

[19:20] Psychologist: Is there any time that would remind you to do it? I like to think about it going to sleep, for instance

[19:21] Caregiver 2: Bedtime will be best for me.

[19:21] Caregiver 1: when multitasking becomes too much, I will sit down and breathe

[19:21] Psychologist: That's a great cue.

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Highlights

- We explored the feasibility of a live, virtual-reality support group.
- Participants were non-professional caregivers of loved ones with dementia.
- Intervention lasted 8 weeks and was based on CBT Principles.
- Perceived depression, stress, and loneliness were reduced post-intervention.
- Participants found the group accessible, convenient, and above all, meaningful.

Figure 1. Screenshot of two avatars in the caregiver support group. Note that when a caregiver is typing, their avatar appears to be typing as well (caregiver on the right).

Figure 2.
Screenshot of the room in which the caregiver support group was held.

Figure 3.

ANOVA analyses of self-reports from pre- to post-intervention; N=6 (one participant's pre-intervention data was lost).

Table 1

Demographic Characteristics

	Caregivers (N=7)	
	Mean/N	SD/%
Age (range)	60.86 (54–70)	12.64
Gender (Female)	7	100%
Ethnicity (non-Hispanic)	6	86%
Race (White)	7	100%
Employment	Full time: 3	43%
	Unemployed: 1	14%
	Retired: 3	43%
Education (Post graduate)	3	43%
Length of AD Diagnosis	3.86	2.23
Alcoholic drinks per week	0.41	0.98
Non-smoker	7	100%
Relationship to person with AD	Daughter: 5	71%
	Spouse: 3	43%
	Sister: 1	14%
In other therapy/support group	3	33%

Table 2

Satisfaction question responses

Satisfaction with online support groups	Answer Anchors	Percent or Mean (SD)
Would you recommend this type of online group to a friend?	Yes/No	Yes = 100%
How much will you use the information learned from the group going forward?	1= Not at all 5=Definitely	3.7(0.8)
How applicable was the information from the group to your own caregiving situation?	1= Not at all 5=Completely	3.43 (0.5)
Did you feel that you came to know the other members of the group?	1= Not at all 5=Definitely	3.2 (1.1)
Did you feel supported by the other members of the group?	1= Not at all 5=Definitely	3.4 (1.1)
How strong was your sense of presence, 'being there,' in the online environment?	1=Not at all strong 5=You felt as though you were in the same room with the other group members	4.0(0.9)