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Use of a Multiparty Web Based Videoconference Support Group for Family Caregivers

Mary Guerriero Austrom,

Department of Psychiatry Indiana Alzheimer Disease Center IU Center for Aging Research 355 W 16th Street, Suite 2800 Indianapolis IN 46202

Kristin N. Geros,

IU School of Medicine kgeros@iupui.edu

Kimberly Hemmerlein,

IU Center for Aging Research Regenstrief Institute, Inc. 410 West 10th St, Suite 2000 Indianapolis IN 46202 khemmerl@iupui.edu

Siobhan M. McGuire,

IU Center for Aging Research Regenstrief Institute, Inc. 410 West 10th St, Suite 2000 Indianapolis IN 46202

Sujuan Gao,

Department of Biostatistics IU School of Medicine Indiana Alzheimer Disease Center 410 West 10th St, Suite 3000 Indianapolis IN 46202 sgao@iupui.edu

Steven A Brown,

Department of Biostatistics IU School of Medicine Indiana Alzheimer Disease Center 410 West 10th St, Suite 3000 Indianapolis IN 46202 browstev@iupui.edu

Christopher M. Callahan, and

Department of Medicine IU Center for Aging Research Regenstrief Institute, Inc. 410 West 10th St, Suite 2000 Indianapolis IN 46202 ccallaha@iupui.edu

Daniel O. Clark, PhD

Department of Medicine IU Center for Aging Research Regenstrief Institute, Inc. 410 West 10th St, Suite 2000 Indianapolis IN 46202 daniclar@iupui.edu

Abstract

This article describes a pilot of a weekly web based videoconference support group for 5 caregivers of persons with dementia. All participants reported positive views of the group and videoconference medium. Improvements in caregiver anxiety, depression, and physical health scores were observed. Depression scores remained the same with burden increasing slightly. Self-efficacy for controlling upsetting thoughts and responding to disruptive behavior improved but worsened slightly for obtaining respite. We concluded that web based support was a positive experience for caregivers, providing them with an acceptable, feasible, low-cost technological alternative to in person support that reduced barriers to attendance by being available in homes.

(corresponding author) maustrom@iupui.edu.

Keywords

web based support group; feasibility; acceptability; dementia; family caregivers; technology

Background

The majority of persons with Alzheimer's disease (AD) are cared for by family caregivers. Approximately 15 million caregivers provide care to persons with dementia and AD nationally in the United States (Alzheimer's Association, 2013). It is well documented that providing care for a dementia patient has negative consequences on caregiver health and wellbeing including high levels of stress, depression, physical symptoms, and psychosocial problems (Sorensen, Pinquart, & Duberstein, 2002).

An increasing number of studies have shown that caregiver support groups where members are attentive and supportive to each other and share experiences and knowledge are able to help individuals relieve the pressures and burdens of caregiving (Chien & Lee, 2008; Gavrilova et al., 2009). While support groups are available in most U.S. communities, caregivers underutilize such services. Time constraints, lack of respite care, transportation, and health issues have been identified as reasons for non-participation in face-to-face caregiver support services (Galinsky, Schopler, & Abell, 1997). In response, efforts have been increasing to offer technology-based support to caregivers. Internet-based interventions are a convenient alternative to other forms of support as they allow caregivers contact with other caregivers and professionals for meaningful guidance and mutual support without the typical constraints of time, travel, and lack of respite care (White & Dorman, 2001).

Powell et al (2008) suggest that technology based interventions show the potential to alleviate caregiver burden and prolong community living but further evaluation is needed in larger trials with good follow-up. Short-term results of technology based programs for dementia caregivers have shown an increase in decision confidence and reductions in emotional strain, spousal conflict, and activity restriction (Bass, McClendon, Brennan, & McCarthy, 1998; Brennan, Moore, & Smyth, 1995). A large body of evidence from Marziali, Donahue and Crossin (2005) has demonstrated that an online format can provide education and support to family caregivers. The purpose of this pilot project was to assess the feasibility and acceptability of a web based video support group offered in real time for family caregivers of persons with dementia.

Methods

We used a web based video support group to provide a forum for caregivers of persons with dementia. This study was approved by the Indiana University-Purdue University Institutional Review Board.

Participants were caregivers of persons with dementia who were recruited from the Clinical Core of the Indiana Alzheimer Disease Center and the Healthy Aging Brain Center at Wishard Health Services, both affiliated with the Indiana University School of Medicine in Indianapolis, IN. Clinic staff notified a research coordinator (RC) of possible study

participants. The RC called the caregiver to describe the pilot and set up a home visit to collect initial assessments and set up the necessary computer software with participants. Written informed consent was obtained during this visit. All caregivers of persons with dementia within these two settings were eligible for study participation.

A web based video support group was held once a week for six months, facilitated by MGA. This was a psychosocial educational support group similar to what we developed for our collaborative care study (Alder, Callahan, Boustani, Hendrie, & Austrom, 2012; Austrom, Hartwell, Moore, Perkins, et al., 2006; Austrom, Hartwell, Moore, Boustani, et al., 2006; Callahan et al., 2006; Guerriero Austrom et al., 2004) and followed the following format:

1. check-in/introductions (10 min),
2. education based on group participant identified needs (20 min),
3. question and answer (15 min), and
4. sharing and support (15 min).

This was modified if there were any pressing needs that required immediate attention. We also scheduled guest speakers for three sessions to cover content in genetics, genetic counseling, elder law issues, and community-based social services. The research assistant (RA) called participants the day of the meeting to remind them of the group and helped them to log-on to the computer program. Participants had access to the educational modules developed for our collaborative care program, which has been described elsewhere (Alder et al., 2012; Austrom, Hartwell, Moore, Perkins, et al., 2006; Austrom, Hartwell, Moore, Boustani, et al., 2006; Callahan et al., 2006; Guerriero Austrom et al., 2004). Alzheimer's Association brochures in digital or hard copy format were available as well.

Each participant was given off-the-shelf desktop computer equipment, which has the advantage of lower cost and greater generalizability. A basic DSL or cable broadband Internet service was used for all participants (200 Kbps speed was needed which is well below standard broadband speeds). We used the Cisco MOVI program, and the video support group was protected with the Advanced Encryption Standard (AES) and “locked down” once all participants were in so that no one else could enter.

Technical support was available by the research team as needed. Remote computer access software was used to allow the RC or RA the opportunity to immediately fix any software issues. The RC or RA would make another home visit to address any hardware or Internet issues.

During the initial home assessment, several baseline measures were obtained. Demographics included caregiver age, gender, education, and relationship to elder. We assessed at baseline and follow-up caregiver depression using the Patient Health Questionnaire (PHQ-9), (Kroenke, Spitzer, & Williams, 2001) caregiver anxiety via the Generalized Anxiety Disorder (GAD-7) questionnaire, (Spitzer, Kroenke, Williams, & Lowe, 2006) caregiver perceived health and quality of life via the Short-Form 36 (SF-36), (Stewart, Hays, & Ware, 1988) caregiver burden using the Caregiver Burden Scale, (Cummings et al., 2002) and caregiver self-efficacy using the Revised Scale for Caregiving Self-Efficacy (Steffen,

McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002). We also held a post-intervention focus group to obtain feedback about the pilot, caregivers' experience with participation via web based video support groups, the use of the technology, and interest in continuing participation using the Internet. Mean and standard deviation of outcome measures at baseline and six months were calculated. In addition, mean differences in scores from baseline to six months and percentage of caregivers with improved scores were also reported.

Results

We enrolled five caregivers into the pilot study (Table 1). One caregiver did not complete the full six-month intervention period; after two sessions she did not feel it would benefit her to continue in the program because she felt her spouse with dementia was not as "bad as the others, her stress was not as severe, and she was just fine". All of our caregivers were female, with a mean age of 56, average of 14.9 years of education, and the majority cared for a spouse. Attendance was 83% for the duration of the intervention (80 of 96 person sessions were attended by all four caregivers).

We noted improvement in caregiver anxiety and depression. Anxiety scores changed from 8.0 at baseline to 6.5, a mean difference of 1.5. Similarly, depression scores decreased from 8.3 to 5.0 with a mean difference of 3.3, respectively. Caregiver burden increased slightly from 41.3 to 42.3 (mean difference of -1.0). Caregiver self-efficacy improved in the subgroups of controlling upsetting thoughts and responding to disruptive behavior, but worsened in the realm of obtaining respite. Our caregivers' perceived physical health scores improved from 51.1 to 53.8, but were relatively the same for mental health (see Table 2).

Qualitative data from the focus group feedback reflected three main themes regarding the benefits of the web based support group:

- education,
- emotional support, and
- logistics.

Caregivers mentioned their appreciation for the guest speakers, most notably the social worker and geneticist. They commented on the application of the content outside of the support group, particularly the information provided by the elder law attorney. For example, two of the caregivers were able to use the information to begin financial planning for themselves. In addition, information from our social worker facilitated the enrollment of two of the patients in a local adult daycare program. After the pilot, the group felt that they "probably could stay connected because [they] have been through so much together," but also cautioned that "being without a leader might be difficult."

The majority of the focus group discussed the positive and negative aspects of social support provided through web based video support. One caregiver said, "the only thing we missed out not being in person was hugs." Another said it was, "not exactly the same, the pros outweighed the cons of not meeting in person." Caregivers felt participation in the group

decreased their stress and it was helpful for them to know that others were going through similar experiences. As one caregiver said, “we get people all day asking how are you and they don't really care; we got something else here.”

Caregivers discussed many benefits of the web based video support group. They described the lack of travel as a significant benefit to participation. Some of them could not take time off work, others could not leave the person with dementia alone, and still others mentioned that finding a convenient meeting location would be difficult; all of these issues became non-existent within the web based support group format.

The caregivers also mentioned that the computer program was easy to use and found the research team helpful with any technology issues. Initially, they felt that meeting once a week might be too much, but once they had been in the group for a few weeks they felt this was an appropriate amount of time and even considered that meeting more often might be a better option. One woman commented “I would find it hard to meet every week, but when I didn't I missed it. I missed the people.” Another caregiver said, “I don't think every other week is enough. It should be once a week.”

Discussion

This paper reports on the feasibility, acceptability and outcome measures of the results of a pilot study of a six-month web based support group for caregivers of persons with dementia. Overall, participants reported very positive experiences and the desire to continue with further group meetings. With this in mind, we felt we would be remiss if we did not remind our participants when the end of the pilot was approaching, in addition to supplying information about in person support groups near their homes. Participants continued to have access to the collaborative care education modules and the Alzheimer's Association information once the pilot had ended.

Although our numbers were small, the data showed trends towards improvement in several caregiver domains. This was noted for anxiety and depression, perceived physical health, and the self-efficacy domains of responding to disruptive behavior and controlling upsetting thoughts. It was surprising to us that the subscale for obtaining respite in the self-efficacy measure showed a worsening at 6 months even though two of the caregivers successfully enrolled their family member with dementia in a local day care program. Given the small sample size in the pilot study, it is difficult to assess why this was the case. A study with a larger number of participants is needed to explain this finding.

We saw a slight increase in overall caregiver burden-- two of the four caregivers improved on the score, one stayed the same, and one scored worse at 6 months. It should be noted that one caregiver in our sample was providing care to a spouse with AD, a mother with AD, and a father with terminal cancer. She had moved her parents in with her to be able to manage all three of them and the father passed away during the course of the pilot study. We also believe that burden scores may have continued to improve for the group had the pilot lasted longer. As we found in our original collaborative care model, caregiver stress and strain was higher at six months than at 18 months post intervention (Callahan et al., 2006).

Most beneficial were the qualitative experiences shared by the caregivers during the support sessions. Our focus group found many benefits to the program, particularly in stress reduction. Caregivers commented on the inability to physically comfort each other, but the benefits of meeting once a week in their own home outweighed this drawback. Most traditional in person support groups meet once a month, but the web based video support group is an easy way to increase the exposure to other group members with little to no problems associated with it. Participants were very engaged and reported the emotional support, real empathy and compassion from the group delivered conveniently in their home were the best parts of the pilot study. The technology allowed the facilitator and all participants to see one another's faces and body language. An important application of this was seen in 1 case where the person with dementia would repeatedly try to leave the home through the back door, which the facilitator and other members of the group could see. This prompted a valuable educational session on the importance of safety, understanding the person's need to wander safely and recommendations that all participants be registered in the Alzheimer's Association's Medic Alert/Safe Return program. Observation or wandering in real time was more effective than discussion or written material alone. This is consistent with recent findings in which caregivers who chose a web based video support group were more engaged and received great benefit when compared to a web based chat group (Marziali & Garcia, 2011).

The use of technology did not pose a barrier during our study. Currently, there are several web based programs that can be used for this type of support group. Some of them include Cisco JABBER Video (the upgrade to the MOVI software that we used), Microsoft's Skype, or Google's Hangouts. We recognize that having research assistants available with technical support was a component of its feasibility, but this can be dealt with in advance by preparing documents for participants with frequently asked questions and showing step-by-step log-on instructions. Other studies have shown that simply having remote access to a password protected, encrypted website that includes technology training manuals and information guides are considered acceptable by family caregivers (insert Marziali citation).

We are aware that this was a small study, making generalizations to all caregivers difficult. However, this technology lends itself easily to a larger scale study, with the flexibility of the program being one of its biggest benefits. Future directions for research include assessing the number of sessions per week or month needed to improve caregiver outcomes. We feel that once initial problems and challenges are addressed, it may be acceptable for the group to continue to meet twice a month or on an as-needed basis. As one of our caregivers said, "being a caregiver is like an addiction. At any time we could drop the ball and need to be helped." Using this type technology makes intervening on an as-needed basis quite feasible given the ease of use and the lack of travel involved.

Utilizing a web based platform for caregiver support groups is acceptable, feasible, and low-cost. That support groups are beneficial has been well documented (Chien & Lee, 2008; Fung & Chien, 2002; Zanetti, Metitieri, Bianchetti, & Trabucchi) and we believe using technology may be a way to reach more people and reduce the barriers to support group attendance like time constraints, lack of respite care, or transportation (Galinsky et al.,

1997). Indeed, as these caregivers shared, as much as they missed being in person with the other caregivers, the benefits outweighed the cons.

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Table 1

Caregiver Demographics (n=5)

Variables	Mean	SD
Age	56.2	5.0
Female, %	5	100%
Years of education	14.9	2.1
Relationship *		
Spouse	4	
Parent	1	
Friend	1	

* One caregiver cares for both her spouse and a parent

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Table 2

Summary of pilot study results (n=4)

Variables	Baseline		6 month		Mean Difference	Percent Improved (%)
	Mean	SD	Mean	SD		
GAD	8.0	7.3	6.5	6.1	1.5	75
PHQ-9	8.3	3.6	5.0	1.4	3.3	75
Caregiver Burden Scale	41.3	18.9	42.3	12.4	-1.0	50
Caregiver Self-Efficacy						
Obtaining respite	60.3	31.7	49.8	38.3	10.6	25
Responding to disruptive behavior	64.3	25.6	65.8	29.1	-1.5	25
Controlling upsetting thought	65.5	11.1	75.0	10.9	-9.5	100
SF36 Physical Component Scale	51.1	2.0	53.8	4.7	-2.7	75
SF36 Mental Component Scale	31.4	4.2	31.2	3.9	0.3	50