Teleconferencing as a Source of Social Support for Older Spousal Caregivers: Initial Explorations and Recommendations for Future Research

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Abstract

Teleconferencing is increasingly being used as a medium of delivering social support for dementia caregivers. Further direction is required from pilot studies before the optimal clinical service can be delivered. Following a 6-week pilot support group for spousal caregivers, delivered via teleconferencing software, we interviewed 8 participants for their feedback. Semi-structured interviews were conducted and analyzed using grounded theory analysis. Themes of "group processes" and "barriers," containing subcategories of "functions of the group," "responsibilities of facilitators," and "barriers to communication" were discussed. According to caregivers, successful teleconferencing support groups should acknowledge the caregiver as the dementia expert, allow participants to meet before the deployment of the support group, provide active facilitation and leadership via the researcher, employ user-friendly technologies, and facilitate for the group to self-maintain following the pilot deployment period. These issues should be taken into consideration when designing future teleconferencing applications for caregivers.

Keywords

qualitative, grounded theory, social support, caregivers, dementia, older

Introduction

Caregivers of older adults with dementia frequently report high levels of burden. Eighty percent of all home-based care is provided by informal family caregivers[1] and as such, caregiver well-being can have economic as well as psychological ramifications.[2] Particularly, depression, anxiety, social isolation, and stress are elevated among caregivers when compared with the broader older adult population.[3,4] Since caregivers are prone to such negative health problems, it is imperative to find efficient and effective ways in which to provide support. Despite the risk factors associated with caregiving, little support is typically offered.[5] It is important to acknowledge the health problems associated with caregiving and to develop potential interventions to prevent these problems. For instance, one can focus upon the caregivers' need for social support and ways in which to address this need. The provision of social support would be especially beneficial to caregivers, since this is typically diminished.[6,7] In a review of 40 psychosocial interventions for caregivers, Cooke and colleagues[8] found that the majority had involved a social component. Telephone-based social support for caregivers has been evaluated favorably.[9] Telephone conference calls are typically peer-based and constitute a flexible and convenient method of providing social support. Telephones are suitable for an older, potentially less mobile population, and may be less likely to interfere with caregiver duties than physical visits to support group meetings.[10] While internet-based interventions are increasingly being offered, with much reported success,[11-14] their uptake is contingent upon participants' level of comfort with computer technology, whereas telephones are a familiar and ubiquitous resource locally. Smith et al[15] reported that users of a telephone peer support group felt they had connected with peers who were having similar experiences, as well as being able to share problems, information, and solving individuals' problems as a group. Stewart and colleagues[16] reported that a telephone peer support group met reported needs for affirmation and emotional support, sharing information, and increased coping skills, confidence, perceived capability, as well as the opportunity to learn from the experiences of others.[17] Multicomponent telephone-based programs, including aspects of support such as

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educational support, as well as social support, have been shown to be more effective in improving caregiver outcomes such as psychosocial well-being.[8,18,19]

Telephone-based support groups may increase the size of the social network available to older caregivers also,[20] which may mitigate the effect of caregiver burden on psychological well-being.[21] Winter and Gitlin[10] evaluated participants after a professionally-led telephone support group and found that after 6 months, scores on depressive symptomatology had decreased significantly. These studies highlight the potential for conducting telephone support groups for caregivers of persons with dementia (PwDs).

The design of telephone peer support groups has not, to date, been prescriptive. Some groups are professional-led, while others are peer-led. The properties of the support group, such as the length of the intervention, frequency of calls and attendance, and the number of components in the approach[22] as well as having a structure to calls[23] can determine whether it is useful for caregivers. Users have been reported to request peer control of calls, while professional support remains available.[24] Salfi and colleagues[23] interviewed caregivers about what they wanted from a telephone support group and responses included education and information provision, referral or assistance, emotional support, and hassle-free, convenient caregiver support. Ploeg and colleagues[25] found that socializing, instrumental, informational, and emotional support were all identified by caregivers as needs that could be addressed using a telephone support group. We previously interviewed participants on their needs in particular relation to social support.[26] Participants told us that they were primarily concerned with attaining educational and informational support, informal support (eg, having an emotional outlet), perceived social isolation, and with their spousal relationships.

The aim of the current study was to deliver a teleconference-based peer social support group for older adults caring for a PwD in the home and then to evaluate the group based on participant feedback. Evaluations were made using semi-structured interviews and qualitative analyses. The intervention described in the current study was then based on the themes extracted from the interviews, directly in terms of the informative broadcasts played during the calls. In a more general sense, the interviews informed the purpose of the intervention to mitigate the deleterious effects of reported social isolation on caregiver well-being. The current analysis outlines participants' opinions on the 6-week deployment of a social support group utilizing teleconferencing, which was gathered using semi-structured interviews. Grounded theory analysis was used to analyze the transcripts created from the interviews. The main aim of the current analysis was to provide recommendations for future deployments of social support groups delivered using teleconferencing software.

Method

Participants

Eight spousal caregivers were recruited via their spouses' attendance at the Memory Clinic at St James's Hospital,

Dublin. The age range of the caregivers was 43 to 82 years (3 female; only 1 caregiver was older than 66 years). All participants were married to a PwD who was living at home. The stage of dementia of participants ranged from early to late, diagnosed following neurological, psychiatric, and neuropsychological assessment at the Memory clinic. All participants lived in the greater Dublin area. Before participating, all participants were provided with an information sheet describing the purpose of the project and provided written informed consent. The study was approved by the ethics committee at St James's Hospital.

Design

We employed a qualitative research design whereby semi-structured interviews were employed to yield participants' opinion on the 6-week social support group. The researcher visited the participants' homes after this time to conduct the interviews.

Procedure

The calls took place twice weekly over 6 weeks. A voice over Internet (VoIP) service was used to conduct all conference calls. The VoIP connected with participants' home telephones or mobile telephones, according to their preference. When a call was due to take place (according to a prearranged schedule), the participant's phone would ring. When they answered the call, an automated message invited them to join the conference call. The participant could join the call by pressing "1" on the keypad or reject the call by pressing "0." Once all callers had accepted the call, the researcher took a role of attendees. The conference calls then started with a short audio broadcast related to topics in dementia care, lasting 3 to 5 minutes. The broadcast topics were listed in the schedule provided to participants and were chosen based on previous interviews with the caregivers.[20] These broadcast topics were; "about dementia," "assistive technology," "communicating with people with dementia," "keeping active," "maintaining everyday skills," "memory impairment in dementia," "practical tips in caring for a PwD," "safety in the home of a PwD," "sleeping and caregiving," and "tips for self-care for the caregiver."

Following the broadcast, the researcher invited participants to have a discussion. The researcher played no further part during the calls, other than to take minutes of the conversations, particularly when tips and services were recommended. The calls lasted 30 minutes. One session toward the end of the 6 weeks was cancelled due to bad weather, as the researcher could not make it to work to operate the VoIP software. The mean number of attendees out of the total of 8 participants was 3.4 (median = 3.5, mode = 5).

After the 6 weeks of conference calls, participants were revisited at their homes for a follow-up interview. The protocol employed was a semi-structured interview, focusing on participants' experience of the conference calls and suggestions for improvement. Each interview lasted approximately 30 minutes.

The interviews were loosely structured around the following questions:

1. In general, how did you find the experience of the support group?
2. What did you think of the broadcasts at the start of the calls?
3. Did you think the set-up worked well? Did you think the sessions were helpful?
4. Would you be more interested in using computer-based support groups, face-to-face support groups, or telephone-based support groups?
5. How did you feel about the length of the study (6 weeks)? Did you feel it was too long or too short or the right length?
6. Is there anything you would change about the project if we ran it again? Is there anything you would change about the set-up of the calls?

All interviews were audio recorded and transcribed for further analyses. Grounded theory analysis[27] was employed to extract themes and categories from the data. The first stage of analysis ("open coding") involved reading the material and identifying key concepts discussed. The second phase of the analysis ("axial coding") involved grouping related codes together to form categories and subcategories. The third stage of analysis ("selected coding") involved grouping the main categories into broader themes. Qualitative analysis was performed by the interviewer, in an iterative fashion, and results were then checked for clarity and for appropriate use of the grounded theory method by the other 3 authors, 2 of whom had significant prior experience in qualitative methods. Issues identified were then settled by discussion until consensus was reached.

Results

Open coding revealed 11 subcategories. The organization of the subcategories, achieved through axial and selected coding, is presented in Table 1. Each category and theme will be presented with reference to direct quotes from the interview transcripts for illustrative purposes. The first theme was labeled "group processes" and included the categories "relating to others," "functions of the group," and "responsibilities." The second theme was labeled "barriers," which included the categories "barriers to communication" and "technical issues."

Group Processes

Participants felt that the processes and dynamics of the group were central to their experience of the intervention. Subcategories of this theme were relating to others, functions of the group, and responsibilities.

Relating to Others

Participants reported that they felt they could relate to one another during the calls, typically reporting identifying in particular with 1 or 2 other participants; "I found a certain affinity with [him]," and relating their own coping mechanisms to those reported by others. "People are quite different in their approach, in how they were about it . . . it's like people coping in different ways." Participants reported identifying with behaviors described by other caregivers also; "I don't read stuff 'cos I get depressed reading it, I don't want to know what's ten years down the road, you know. And I think [they] both said one day, they don't do it either." Relating to others provided a basis for social comparison, which proved helpful for caregivers reflecting on their own situations; "it helped me to clarify as well what I needed." It is clear that identifying with the other caregivers by relating self to others in the group is a prerequisite to sharing and offering support and solidarity.

Participants related their situation and their spouses' conditions to those of the others also. Dementia-related behavior was discussed; "[he] said his wife seemed indifferent to him, whereas [my wife] is social, she needs comfort all the time." Comparing to individuals whose spouses were more progressed in dementia appeared helpful for some participants; "he got it worse than I'm getting it, you know? He seems to have come through the mill, he got a rough end. But my wife's not too bad, you know." This process of comparison allowed caregivers to learn how others managed their situations and also to reflect on their own approach, which, according to social comparison theory,[28] can improve self-efficacy. It was observed that only participants whose spouses were at an early stage of dementia employed social comparisons.

Functions of the Group

Participants spoke about the "social outlet" function and the "educate each other" functions of the group. Participants reported that they enjoyed the social aspect of the calls; "it was good to get in touch with other people, you know, just to hear other people's stories and all of that," and acknowledged their need for social support from other caregivers in particular; "I think in A.A. [Alcoholics Anonymous] they had a thing called a buddy system, maybe even a pair or a triad or something, but it might be worth considering . . . so someone can say, I'm actually really pissed off, I'm really sick of it, and they can ring somebody who knows." This acknowledgement confirms the need for social support provision among this population. In terms of "educating each other," participants shared tips and advice which was greatly appreciated; "It's an educative effort, this is a learning event, and people were learning lots from each other."

Responsibilities

The category of responsibilities related to the division of group duties across the researcher and participants. Caregivers reported that it was important for the researcher to acknowledge the "caregiver as expert" since caregivers are more knowledgeable and experienced than the researcher in the subject of caregiving, a comparison that they felt was particularly typified by the content of the broadcasts; "the people in the group knew far more

Table 1. A Summary of the Themes, Categories, and Subcategories that Emerged From the Grounded Theory Analysis

Theme	Categories	Subcategories
Group processes	Relating to others	Relating self
		Relating situation
	Functions of the group	Social outlet/getting in touch
		Educating each other
	Responsibilities	Acknowledging carers as experts
		Maintaining the group
		Supporting the group
Barriers	Barriers to communication	Social constraints
		No knowledge of others
	Technical issues	Openness to new technologies
		Situational issues

than the person reading out the thing." Rather, caregivers would have preferred to start the conversations themselves and did not feel that the broadcasts were necessary; "Obviously, when you say I'm talking about stress today, that goes out the window very quickly, it still comes back to how you're managing day to day, still comes back to your own personal experiences." Caregivers also reported that researchers had the responsibility of "maintaining the group" after the completion of study, to allow the caregivers to continue to support each other in a self-sufficient manner; "if it was tweaked a bit, once a week would be sufficient, or once a fortnight, or it mightn't need to be too often." Caregivers also felt that researchers had a responsibility toward "supporting the group." While the current design dictated that the researcher did not get involved in the conversation, caregivers felt that more participation would have provided a structure and support to calls; "what I would find with the person who's monitoring the call . . . probably have a little bit more involvement to say, well [she] hasn't said anything now in the last ten minutes, and what do you think, what would your opinion be, that sort of thing." Researchers were also expected to support the group by debriefing participants including the dissemination of logged minutes from the calls, such as tips on coping; "the information was good, it was helpful. And you're going to send that around?" One caregiver felt that the researchers were more concerned with the research agenda than with providing support, since they did not engage during the calls; "it's like, we'll let them off and see what happens, and why would you do that with people[1]?"

Barriers

The second theme to emerge from the interviews was that of barriers, divisible into 2 categories; barriers to communication and technical difficulties.

Barriers to Communication

The use of the telephone caused social constraints for some participants; shyness in part precluded some participants from engaging in a group call; "a lot of people were shy of it though." Turn-taking was also an issue because of the lack of visual cues, leading to pauses in conversation and people talking over each other; "There's confusion with, yeah, and then saying, they wait for someone else to say something they've already heard it, and they go to say something again," leading some participants to report feeling left behind by the conversation; "I got most of them but I got a bit lost you know, it's all very confusing you know, you're not getting everything." Hearing difficulties also precluded successful communication at times. Another barrier to communication was the "lack of knowledge" participants had of each other; "people might have made more effort to participate if they had some knowledge of the people they were meeting." Participants felt that this led to a reticence to disclose and a difficulty in maintaining conversation, particularly at the start of the intervention period. Participants suggested that being given the opportunity to meet the others prior to the study may have alleviated this difficulty; "even if it might be an inconvenience . . . if the participants had at least some knowledge of one another . . . even if they met once or something like that so that you could put a face to the voice," which may have been difficult considering the accessibility issues common to this population.

Technical Issues

Technical issues discussed included "situational issues" precluding participation and "openness to new technologies." Situational issues included making the time to take the calls; "I made a special effort to participate because I felt that if I commit to something I like to try and stick with it," which was easy because the calls were enjoyable to most participants; "I looked forward to doing it, rather than thinking, oh I have to do that, I was actually thinking, oh I've got this on today, I mustn't forget that! So once I had the time, I was very willing to participate." One participant reported sensitivity toward his spouse as a situational issue; he used his mobile phone outside of the family home to take the calls because he felt that if his wife knew he was seeking social support, she would feel burdensome; "If she knew she'd be very upset." Generally, the telephone medium was viewed quite positively; "you're in your own home, you're in a safe environment, with your wife or husband or whoever, and you can communicate and have a chat over the phone, so in a way it's a good idea".

Openness to New Technologies

Caregivers varied in their previous experience and comfort levels with new technologies. Willingness to adopt may have also been affected by the sound quality of the calls and other technological issues; "there was one little flaw, there was a time lag[2] on it, and that could be got around, you know?" Most of the participants already used Information and communication technologies (ICT) and the Internet to access information about dementia; "I look up the Internet, look up different websites or mail . . . I use the odd Skype call or the odd emailing."

Discussion

Thecurrent investigation aimed to qualitatively elicit recommendations for the structure and provision of social support to spousal caregivers of older adults with dementia. On the whole, feedback was positive, and several recommendations for future research and clinical implementation were revealed. These recommendations will be discussed, alongside the methodological limitations of the current study, and future directions for the provision of social support for spousal caregivers. Two broad themes were elicited from caregivers in discussing the social support group; group processes and barriers. Caregivers appreciated the opportunity to compare their situations and create relationships based upon the shared experience of caregiving. Sabir and colleagues[29] previously investigated the necessary elements to build successful support and found that rather than shared commonalities such as age, gender, education, and so on it was in fact the shared experience of caregiving which brought most people together. The group in the current study could successfully identify themselves as group members due to this shared experience. Caregivers also employed social comparison, but only when their situations were perceived as being more manageable than those faced by the other caregivers. This process is known as social downgrading and is often used by older adults in comparison with their peers.[30] This process could recommend the inclusion of participants whose spouses are at different points of decline with dementia, to allow for social comparison to occur. Participants also reported that they appreciated tips and information offered by other participants, which accords with previous research reporting the caregiver's need for informational support provision.[15] This type of support could be uniquely available from other caregivers, since friends and family would not have the same expertise. In terms of responsibilities, the finding that caregivers wanted to govern the conversation themselves accords with previous research.[16] Acknowledging caregiver expertise could also be an opportunity to empower, increasing self-efficacy and reducing caregiver burden.[31] Caregivers also wished that the support group could have been maintained over a longer duration, which was not possible during the current investigation due to limited resources, but could be investigated in future research. Another issue was the lack of support felt from the researcher, but this may have resolved itself had the group ran over a longer period, since a natural group leader would likely have emerged. Researchers facilitating support groups may need to become more involved in the individuals' interactions, and support the caregivers as they support each other, in order to demonstrate that the individuals' needs are being prioritized ahead of the research outcomes.

The second theme of barriers explored issues preventing the effective provision of social support across caregivers. Many issues raised were technical in nature and these are issues inherent in teleconferencing technology, which could not be addressed within the confines of the current project. However, they must be borne in mind when designing social support groups, as different media may be more suitable for people with hearing or vocal difficulties (one participant had had recent laryngeal surgery, which made it difficult for her voice to be heard on the calls). The lack of a face-to-face meeting made participants slightly uncomfortable talking to each other, and this may be resolved by providing one such meeting before the deployment of future telephone-based support groups.

Overall, it appeared that the use of telephones constituted a convenient solution for spouses of PwDs, since the mobile phone could be used to allow a private call for those whose spouse is in the early stages and may be sensitive if they hear their spouse attending a support group. It is also convenient for spouses of persons with advanced dementia who may find it difficult to attend face-to-face meetings because of respite issues.

While on the whole, caregivers reported that the group met many of their needs, the system requires some find-tuning. Participants felt able to connect with and relate to each other, felt socially connected, shared experiences and learned from each other, and learned to reflect upon their own situations, as a result of participation. While the provision of social support via telecommunication is ideal for some caregivers, who value privacy and convenience, others are unhappy with the lack of visual cues, which can make conversation difficult. This is an inherent issue with telephone use and it is more than likely not possible to suit all caregivers using one medium. In terms of methodological limitations, the sample size was small. Eight participants took part, and there was little variation in socioeconomic status and education level, meaning that the results may not be generalized to the broader Irish population. Most participants were also involved in external social support groups, which may have contaminated results. Furthermore, the same researcher assessed caregivers before and after the intervention, which may have caused unintentional reporting bias. Attrition appeared to be a significant issue in the current study also, and failure to attend the calls may have been due to challenges faced by the caregiver or due to problems with the study itself, which would potentially bias results.

Another potential issue was the duration of the calls. Previous research has varied greatly in the duration of sessions, with the 40 interventions reviewed by Cooke and colleagues ranging between 45 minutes per week and 4 hours per week.[8] The decision to provide two 30 minute sessions per week in the current study is comparatively short and may potentially have affected the efficacy of the intervention. However, due to limited resources, we could not hold longer sessions. Furthermore, the introductory session lasted 1 hour, and some participants complained that it was difficult for them to devote this much time to the intervention. Therefore, brief sessions may be preferable to the busy caregiver.

We included a dual component approach in the current intervention, where both social support and informational support was provided. Multiple component approaches are preferable when providing support to vulnerable groups[8,18,19] and Mulligan and colleagues[32] listed 15 potential components. However, our limited resources combined with the emphasis on peer support and absence of professional involvement meant that 2 components were appropriate for the current study.

The current study represents an exploratory phase of investigation or a pilot study of teleconferencing to provide social support for older caregivers. As such, our recommendations should be employed in larger-scale, controlled investigations to further analyze the efficacy of teleconferencing for providing social support.

Conclusions

We have discussed the caregiver assessments of a pilot teleconferencing support group. The results confirmed previous findings, finding that identifying and supporting group processes and tackling barriers to communication are central to successful support groups. It is apparent that peer support is highly beneficial for caregivers but requires structure and leadership from the researcher. Previous teleconferencing studies have acknowledged that caregivers require both informational and social support,[15,16] so it is of note that the current study fulfilled these needs for participants. Current results indicate that while teleconferencing represents a useful means of providing social support for caregivers, they require leadership, researcher support, familiarity and comfort among participants, and the opportunity to maintain the group long-term in order to be viewed as successful by caregivers. These conclusions should inform future designs of research and clinically implemented social support interventions for caregivers of persons with dementia.

Declaration of Conflicting Interests

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