

Waiting Room Connections: The Role of Informal Support Groups in Addressing

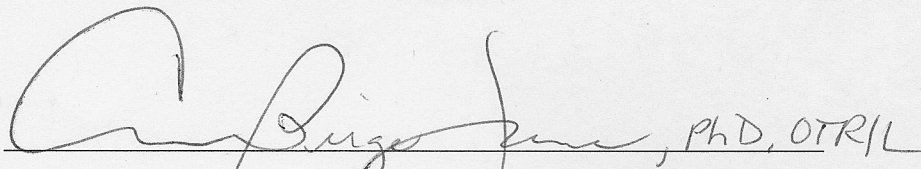
Caregiver Burden


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Abstract

Participation in a formal support group can be an effective way to reduce caregiver burden, providing caregivers with a way to share information and ideas, as well as connect with others who share similar experiences. Occasionally, informal support groups will develop spontaneously when caregivers are gathered together, such as waiting for their family members' therapy appointments. Very little is known about the formation and benefits of informal support groups, which may be valuable to caregivers in unique ways. This study used a qualitative phenomenological approach to investigate the lived experience of three client family members during their time in the waiting room of an on-campus, occupational therapy and physical therapy student clinic, in order to gain a better understanding of the experience of caregivers of stroke survivors and the role of informal support groups. Data were collected from caregivers of stroke survivors via one, 60-minute focus group. The themes that emerged regarding caregiver experience of life after stroke included 1) Daily Life and Future Plans Were Altered, Disrupted, or Lost, 2) Friends Wanted to Help But Rarely Understood, and 3) Caregivers' Emotional Well-Being was Challenged after Stroke. Themes that emerged regarding the role of informal support groups included 4) Friendships Based on Shared Experiences, 5) Shared Information from Others in the Same Boat, and 6) Social Comparisons Can be Helpful or Discouraging. This information may be helpful to occupational therapists and other healthcare professionals by providing them with ways to facilitate formation of informal support groups and encouraging holistic care that considers not only the client but also the context and environment that impact the client's well-being.

Waiting Room Connections: The Role of Informal Support Groups in Addressing Caregiver Burden

Every year approximately 795,000 people in the United States experience a cerebrovascular accident (CVA), also known as stroke (Centers for Disease Control and Prevention [CDC], 2009a). Stroke is a leading cause of long-term disability in the United States (CDC, 2009b). Mobility is reduced in more than half of stroke survivors age 65 and over (CDC, 2009a). Because the majority of clients return home following a stroke, there is often a reliance on family to provide the necessary care (Anderson, Linto, & Stewart-Wynne, 1995). As hospital stays become shorter and the rehabilitation process shifts from inpatient to outpatient, caregivers become increasingly important in recovery and rehabilitation (Anderson et al., 2000; Low, Payne, & Roderick, 1999). Family members may face the task of caregiving with little formal support from healthcare professionals (Jongbloed, 1994). Clearly, it is not only the stroke survivors themselves whose lives are impacted by stroke, as many spouses and family members are significantly affected as well.

As family members and spouses become the primary caregivers for a stroke survivor, they frequently face what is referred to as caregiver burden. Caring for someone with a disability can become a full time position. The caregiver may be responsible for home and community tasks, such as meal preparation, shopping, and managing finances; transportation to and from appointments; and assisting the client with activities of daily living, including toileting, bathing, and feeding. These caregivers may begin to focus much of their time on the dependent relative, therefore decreasing the amount of time they are able to spend on themselves (Bulley, Shiels, Wilkie, & Salisbury, 2010). They

may experience feelings of isolation and abandonment (Kerr & Smith, 2001). A study by Williams (1993) found that two-thirds of caregivers reported sleep pattern disturbances. Also striking in this study was the incidence of psychological distress and feelings of hostility experienced by caregivers. These emotional challenges may be exacerbated by the fact that communication can be lost after a stroke. A caregiver of a spouse with stroke noted, "Living with someone with no speech can be very lonely...I can talk to him and he understands, but he can't respond" (Williams, 2012, p. 24). Not only is the caregiver facing extra burden, he or she may be facing it alone.

Participation in a support group can be an effective way to reduce caregiver burden. Research has shown that "higher levels of social integration and...social support were associated with lower burden in caregivers" (Rodakowski, Skidmore, Rogers, & Schulz, 2012, p. 2231). Not only can the support group provide a social outlet, it can be a means through which to share information and ideas. The support group can connect caregivers with healthcare professionals, providing an opportunity for education (Williams, 2012). Formal support groups are officially recognized, with consistent members and meeting times. Informal support groups often form organically, and may be less structured than formal support groups. Informal support groups are typically not officially recognized.

The literature review revealed articles investigating formal support groups (Hartke & King, 1997; Morris & Morris, 2012; Williams, 2012) but very few articles examining informal support groups (Cohn, 2000). Informal support groups may be equally or more valuable to caregivers. One advantage is that caregivers do not have to take extra time out of their day to attend a support group; rather, it is already built into the

schedule. The lack of literature about informal support groups reveals a gap in our knowledge. In order to understand exactly how informal support groups form and function, further research is needed.

Mental and physical health in caregivers is important not only because they are valued individuals, but also because it contributes to the welfare of the client. A caregiver's well-being influences the client's well-being, and plays a role in the success of rehabilitation. If caregivers have good informal support, it enables them to be successful with necessary tasks without requiring formal support services (Simon, Kumar, & Kendrick, 2008). Stroke costs the United States \$38.6 billion annually, including lost productivity and health care services (CDC, 2009a). Understanding the tools that help us to address the problem of caregiver burden will encourage more effective and efficient care of stroke survivors.

Background

Caregivers of stroke survivors. Estimates have suggested that as many as 74 percent of people with stroke required help with activities of daily living from family caregivers (Dewey et al., 2002). Bulley et al. (2010) found from their interviews with caregivers that "lives turned upside-down" (p. 1406) emerged as the overarching theme. One woman described feeling as though she were a prisoner in her own home. The literature revealed recurring themes of emotional effects, such as depression, social isolation and reduced participation in life, and changes in role and workload in caregivers of stroke survivors (Bolas, Van Wersch, & Flynn, 2007; Bulley et al., 2010; Kerr & Smith, 2001).

There is considerable evidence that caring for someone with a chronic disability, such as stroke, has a profound effect on the caregiver's health, and studies have shown that many caregivers experienced poor psychological health (Carnath & Johnson, 1987; King, Shade-Zeldow, Carlson, Feldman, & Philip, 2002; van Puymbroeck & Rittman, 2005; Visser-Meily, Post, Schepers, & Lindeman, 2005; Williams, 1993). Depression affects up to half of the spouses of stroke survivors, which in turn may have a negative impact on stroke outcome (Rodgers, Francis, Brittain, & Robinson, 2007). Caregivers are also dealing with the emotional and behavioral changes in the stroke survivors, which can affect their own well-being and create a detrimental cycle (Bulley et al., 2010).

Emotional changes are linked to the nature of the caregiving. The participants in a study by Bolas et al. (2007) found caring to be relentless, overwhelming, and frustrating. Caregivers experienced a stigma, which led to secrecy and withdrawal, cutting them off from their social worlds and the benefit of social support. A young caregiver of a stroke survivor shared her feelings of isolation that, in her eyes, saw no end. "Like, it took a lot of me time up when I was caring for me Mam if me Dad went out when I had friends. But like now it doesn't bother us as much because I haven't got friends. So it's alright" (Bolas et al., 2007, p. 838). Limited leisure time and reduced social networks can lead to increased isolation, dissatisfaction and stress. Social isolation is particularly a problem when the caregiver feels that the stroke survivor relies solely upon his or her care and is reluctant to be left alone (Rodgers et al., 2007). These feelings of social isolation may lead to feelings of resentment, decreased self-efficacy, decreased optimism, and lack of perceived control over emotions.

Changes in role and workload can also contribute to the challenge of caregiving. One participant described doing the work for two people due to his spouse's limitations (Bulley et al., 2010). Changes in roles can be particularly difficult for men, as the caregiving responsibilities often bear resemblance to traditional females roles. One husband said, "In our age group, men and women have defined roles. Now it's more difficult for both of us because they are blurred" (Jongbloed, 1994, p. 1010). Because people are defined so much by what they do, any changes to these patterns of daily life can be difficult emotionally as well as practically.

The experience of caring for a family member following a stroke has been the subject of considerable research, although it was largely conducted outside of the U.S. (Bulley et al., 2010; Jongbloed, 1994; Kerr & Smith, 2001). The results of these studies indicated that caregiver burden is significant, both emotionally and physically, and that caregivers need more help in adjusting to their new roles. Kerr and Smith (2001) found that the flow of care from inpatient to outpatient rehabilitation was bumpy for many caregivers. The formal support provided to caregivers was often insufficient and failed to meet the caregiver's individual needs. Jongbloed (1994) suggested that we can no longer view stroke as an individual phenomenon. Stroke affects the caregiver and the client differently, and comes into a pre-existing network of relationships and economic, environmental, and cultural factors. These studies highlight the importance of providing more support to caregivers to ensure that the role is a sustainable one (Bulley et al., 2010).

McPherson, Wilson, Chyurlia, and Leclerc (2010) found that self-perceived burden was prevalent among stroke survivors. Of respondents, more than half (54.5%)

noted that they agreed or agreed strongly with the statement “I do not discuss my feelings with my caregiver because I do not want to cause him/her distress.” Nearly half of respondents also agreed or agreed strongly with “I avoid asking for help from my caregiver so that I do not burden him/her” (McPherson et al., 2010, p. 199). Such results indicate that caregiver burden affects the client as well as the caregiver. Poor communication between client and caregiver, especially if they are spouses, may cause discord or strife. It is also a safety concern if the client does not ask for help when it is needed.

Support groups. Caregiver burden may be alleviated with access to social supports such as formal or informal support groups. Support groups can allow caregivers of stroke survivors to have the focus placed on them. Charlotte Gillian, a member and founder of a stroke caregiver’s support group in Northern Ireland, said, “There are so many benefits [of support groups]; meeting others in the same situation, having relaxing therapies and getting advice and information about caring from speakers. That mix of learning and time out is essential I think” (Williams, 2012, p. 22). Morris and Morris (2012) found that caregivers who participated in peer support groups valued the staff presence, social comparison, and peer support. The findings of a study by Cameron, Naglie, Silver, and Gignac (2013) indicated that support from a range of individuals (health care professionals, family, friends, and caregiving peers) was beneficial for the caregiver. The needs of the caregiver change across the rehabilitation continuum, calling for varying types of support.

Formal support group research has also suggested that social support is beneficial to care receivers as well as caregivers. Winslow (1998) explored in detail a family

caregiver's experience with the use of formal community support services. This qualitative case study found that the formal support group benefited both the caregiver and the person receiving care. Mrs. V, a caregiver, noted:

I feel that I'm not alone in this world with this on my shoulders...The opportunity to share experiences with other caregivers provides a sense of relief...I think I would have just folded up if I hadn't had them. You can talk about things that you think nobody else understands and they do. (Winslow, 1998, p. 17)

Mrs. V also shared her husband's reaction to this formal support group, stating:

He loves it. He doesn't want to stay home now. That's his home. This morning before we got ready to go he says, "Well, when are we going to go? When are we going to see the gang?" So he's really enjoying it. (Winslow, 1998, p. 18)

Unfortunately not all caregivers have access to these formal support groups. Many have limited financial resources and social supports. Support groups may not be as prevalent or appealing in some communities. Because some clients require around-the-clock care, caregivers may not have the time to attend formal support groups. Informal support groups may be able to address caregivers' needs without the barriers that make participation in formal groups a challenge. The casual nature of informal support groups may be appealing to some individuals. Informal support groups tend to develop organically and typically occur at a time and place that is convenient for the caregiver. Perhaps the random, sporadic nature of these support groups makes them function differently. More research is needed to understand the nature of informal support groups and the effects of such groups on caregivers.

A review of the literature revealed one study that examined an informal support group. Cohn (2000) stumbled upon the phenomenon of an informal support group during her research of parents' opinions of outcomes of sensory integration occupational therapy

interventions. Cohn found that many of the mothers found naturally occurring support in the clinic waiting room. “Through their weekly interactions with one another, sharing stories, experiences, parenting challenges, and resources, these parents gave and received naturally occurring support” (Cohn, 2000, p. 172). Although the caregivers in Cohn’s (2000) research were parents, interesting parallels emerge between them and the caregivers of stroke survivors. Both groups seem to experience caregiver burden. In addition, many of the challenges faced by these groups are shared – a lack of social interaction, a decrease in personal time, and an increase in stress.

Cohn also noted that social comparison was an important aspect of the waiting room support group. The mothers were able to compare their children's conditions to others, which helped them to reframe their perceptions and accept their situations. Cohn’s research led her to highlight the importance of expanding the definition of occupational therapy to include interventions with family members (in her case, parents), as well as with patients. “As therapists and researchers, we need to pay attention to the entire context surrounding the intervention process, not just the explicit therapeutic encounter” (Cohn, 2000, p. 172). Cohn also highlighted the importance of creating a waiting room space that fosters conversation between family members.

The formation of an informal support group came to the attention of students and clinical instructors at University of Puget Sound (A. James, personal communication, February 25, 2013). The university offers on-campus, student-run occupational therapy and physical therapy clinics for community members. The informal support group formed in the clinic waiting room among female caregivers of stroke survivors. The caregivers have since asked for their family members’ therapy to be scheduled at the same time, and

the caregivers and their family members often go out to lunch after therapy (A. James, personal communication, February 25, 2013).

The Occupational Therapy Framework: Domain & Process, 2nd edition (American Occupational Therapy Association [AOTA], 2008), refers to the context and environment surrounding the client as reflective of “the importance of considering the wide variety of interrelated conditions both internal and external to the client that influence performance” (p. 642). Context and environment may be less obvious than client factors in people post-stroke, yet they strongly influence participation in daily occupations. Consider the many variables that come into play here, from cultural customs to personal demographics, temporal context to societal behavioral standards (AOTA, 2008). Occupational therapy is most effective when it stays true to its holistic nature and addresses the client in context, respecting the interdependence of task and environment and facilitating client-centered care.

Gaining a better understanding of the formation and effect of informal support groups for caregivers can better inform occupational therapy practice, not only for clients with neurological deficits but for other areas of practice as well. Providing caregivers with support can perhaps help to alleviate caregiver burden and decrease psychological stress. In turn, the caregivers may provide better care for their loved ones, leading to better outcomes for the care receiver. Informal support groups may facilitate communication among caregivers by allowing for the sharing of strategies to facilitate activities of daily living, healthcare referrals, or information regarding community services. Further knowledge about informal support groups can also help healthcare professionals to facilitate their formation. Knowledge about factors that can assist

formation are important, such as intentionally scheduling clients with similar diagnoses at the same time, or designing a waiting room that is welcoming and encourages conversation between caregivers.

The formation of one informal support group in the University of Puget Sound clinic waiting room provided a unique opportunity to gain further insight into the phenomenon of the informal support group, as well as to further our understanding of what caregiver burden looks like and what steps could be taken to reduce it. The purpose of this study was to investigate the lived experience of three to six client family members during their time in the waiting room of an on-campus, occupational therapy and physical therapy student clinic, in order to gain a better understanding of the role of informal support groups and the experience of caregivers of stroke survivors.

Method

A qualitative phenomenological research design was used in this study of caregivers of stroke survivors. Qualitative research uses multimodal methods to study people and events in their natural settings (Stein, Rice, & Cutler, 2013). Phenomenological studies focus on capturing the uniqueness of events within their distinctive political, historical, and sociocultural contexts. Remaining faithful to the participants' own words and personal experiences is critical in this research design (Yin, 2011). This study used a focus group to gather information about the lived experiences of caregivers of stroke survivors and their experiences in the waiting room of an on-campus, student-run occupational therapy and physical therapy clinic. The unique phenomenon of an informal, waiting room support group was best studied in its natural setting, using a research method that enhanced understanding of this complex experience. The benefits of

focus group research include gaining insight into people's shared understandings of everyday life and the ways in which individuals are influenced by others in a group situation (Gibbs, 1997). By allowing the caregivers to describe their own interpretations of their life experiences, the researchers gained insight into a population that demands further study. As is important in phenomenological studies, the researchers avoided predetermined interview questions; structured interviews with fixed questions could have distorted or constrained the data collection and interpretation (Yin, 2011). Data were collected and analyzed as objectively as possible by the researchers in order to gain a clear understanding of the experience of the caregivers.

Participants

Participants of the study were selected from a convenience sample of caregivers of stroke survivors who attend or previously attended (within the past year) the University of Puget Sound occupational and/or physical therapy adult clinic. Eligible participants were those who have been primary caregivers of stroke survivors for at least six months, have spent a minimum of 10 treatment sessions in the Puget Sound on-campus clinic waiting room, and have engaged in conversation with another caregiver at least five times. It is not necessary that the conversations were with the same caregiver. "Engaged in conversation" was defined as a conversation that lasted at least three to five minutes, moved beyond general greetings and superficial social exchanges (e.g., hello, discussion of the weather or sports), and included some discussion of being a caregiver.

The desired number of participants was three to six; due to budgetary and temporal concerns this limit could not be exceeded. Written informed consent was obtained from willing and eligible participants.

Procedures

Approval from the university's Institutional Review Board was received before participants were provided with information about the study. The researchers placed flyers with general information and researcher contact information on the on-campus clinic waiting room tables. In addition, researchers talked with individuals in the waiting room during the physical therapy adult clinic at University of Puget Sound in order to answer questions about the study described in the flyers. Four eligible caregivers verbally expressed a desire to participate in the study and agreed to be contacted via telephone and email regarding the next steps. When called at a later date, three participants remained interested in participating in the study and all participants signed consent forms at a later date. None of the participants' care receivers had been referred back to the occupational therapy or physical therapy clinics at University of Puget Sound.

One 60-minute focus group was conducted at the university in a conference room. A semi-structured interview with a series of questions designed to foster conversation among the participants was used for data collection. Guiding questions were asked regarding the experience of being a caregiver for a stroke survivor, as well as regarding the waiting room experience and the effect it has had on caregiving (see Appendix for focus group questions).

The interviews were audio recorded and transcribed verbatim by a professional transcriptionist. The researchers recorded observations during the focus group in order to enhance data analysis. The transcripts were reviewed and compared by the researchers until all discrepancies had been resolved in order to ensure accuracy. Pseudonyms were

used to protect confidentiality and both the transcribed focus group data and field notes were stripped of all identifying information.

Individual phone interviews were conducted for follow-up questions to supplement the focus group data, as well as for member checking. The follow-up questions were regarding demographic information and clarification about certain statements or experiences that the study participants had brought up during the focus group. Member checking was performed to increase credibility in the study. Written summaries of the focus group data were prepared and shared over the phone with the participants. The researchers verified that the informants' words accurately matched what they intended to say and that the researchers were accurately capturing their views (Shenton, 2004). Member checking was also used to ensure that the participants and researchers had congruent ideas as to the emerging theories that arose during the focus group dialogue. Once feedback was received, necessary modifications were made as a part of the data analysis process. Member checking occurred once, as preliminary themes developed during data analysis.

The researchers aimed to ensure sincerity in the study participants. Each participant was given the opportunity to refuse participation. This ensured that the focus group sessions involved only those who were genuinely interested in participating and freely offered their perspectives (Shenton, 2004). The researchers worked to establish a rapport among the group of participants in order to facilitate and encourage honest and thoughtful communication. The researchers acted as moderators, encouraging participation from all without introducing personal biases or opinions (Yin, 2011).

Peer debriefing was used to increase the trustworthiness of the study. Peer debriefing involved an individual who was not a primary or co-investigator of the study reviewing the data. The chair of the research study assisted with peer debriefing after the data analysis. Periodic meetings with the chair occurred throughout the research process. Collaborative sessions were important to allow the researchers to discuss alternative approaches with a mentor with expertise in qualitative analysis. Flaws in the study and researcher bias may be uncovered when meeting with those in a more supervisory role (Shenton, 2004). The thesis chair was consulted to gain feedback on interview protocols, data collection, and data analysis.

Data Analysis

Each researcher independently analyzed transcribed focus group data and notes from observations for emerging themes and concepts. Semantic maps were created by each researcher to assist in identifying themes. The data were divided into segments or groups based on similarities and differences, and a name or categorization was given to each unit of meaning. This system of coding was completed by both researchers as the data were analyzed separately, to assist with reaching the overall goal of enhanced understanding of the topic (Stein et al., 2013). Code-recode was used to verify emerging themes and concepts. After analyzing the data separately, the researchers came together to compare codes and discuss potential biases to ensure researcher objectivity. After discussion and comparison, the researchers collaboratively agreed upon mutual codes and themes. The researchers conducted a final analysis and revision following the member checking.

Results

Three caregivers of stroke survivors participated in the study in order to share their experiences as caregivers and as members of an informal support group. The caregivers' family members had been living with stroke since 2008 (Clarence and Sara), 2009 (Allen and Lou-Lou), and 2005 (Sue and Joe). All participants described themselves as Caucasian. See Table 1 for additional caregiver and care receiver demographic information.

Several themes emerged from the focus group regarding the caregiver experience and the role of informal support groups for caregivers of stroke survivors. The themes included 1) Daily Life and Future Plans Were Altered, Disrupted, or Lost, 2) Friends Wanted to Help But Rarely Understood, 3) Caregivers' Emotional Well-Being was Challenged after Stroke, 4) Friendships Based on Shared Experiences, 5) Shared Information from Others in the Same Boat, and 6) Social Comparisons Can be Helpful or Discouraging. These themes and the relationships between them are depicted in Figure 1.

Theme 1: Daily Life and Future Plans Were Altered, Disrupted, or Lost.

The caregivers described a change in their expectations of life after the stroke. Comments relayed a sense of loss regarding future plans. Sue became the caregiver for her son after his stroke and stated, "It is a big job." She further explained, "Well, it completely changes your life because you become the caregiver... Probably can't do some of the things that I might have planned to do." Sara also talked about loss of future plans, explaining:

And I think I was the one that was the most depressed. So far as changing our life, it just became, instead of a real flamboyant... every day was our oyster and we could do whatever and go whatever and planned ahead... It became [a life] of therapies two and three times a week.

Sara and Clarence had been making plans to go on a cruise with friends before the stroke. Her husband experienced the stroke in November and the final payment for the cruise was due in January. Sara recalled, "We were positive he was going to be able to go. As the time got shorter, the handwriting was on the wall, and we could see that we needed to make some changes." Sara discussed how the really bad days made it difficult to think about those plans but that they have learned to take it one day at a time. Sara noted that she and her husband currently abstain from long-range planning as a result of the stroke.

Caregivers also described a general change in their participation in life. Sara commented that she has never left her husband alone for a night, limiting the time she could spend with friends on a trip away from home. Sara explained how she would have to have hire someone to stay in the home with her husband, "And at \$34.50 an hour, there wouldn't be a whole lot of money left for my trip." Lou-Lou described a similar situation in which she has only spent one night away from her husband, further explaining that this only occurred because her sister made all the arrangements. Sue, on the other hand, described her situation as different from Lou-Lou's and Sara's, as she is a caregiver for her son as opposed to a spouse. Sue stated, "I have an advantage because I do have a significant other that lives with me. And he has been a very big help, especially when my son first came home." Sue also talked about how caring for significant others or husbands can be different than caring for a son. Sue described how she could tell her son, "Get your butt out there and walk," which is different, as she explained, "husbands don't do like your children do."

Theme 2: Friends Wanted to Help But Rarely Understood

Changes also occurred regarding social participation within two of the three participants' own personal groups of friends. Sara noted that her other friends had good intentions and had a desire to help but didn't understand what she needed or what she was going through. Lou-Lou agreed, expressing her frustration when friends would ask, "How come they are not getting better?" Sara noted that social participation has been limited with some friends because their homes are not wheelchair accessible. This has contributed to certain friendships that have "dwindle[d] away." Sara explained, "They start looking at you guys as a hardship. They don't include you in things anymore because it is hard to get him [Clarence] in the house."

Lou-Lou also experienced a decline in social participation after her husband's stroke. She observed that when her husband first returned home, they had many friends who would visit and offer to help, but this changed over the years. Lou-Lou further explained, "We have friends that have really stuck by and helped and then you have friends that you see once in a while."

Sue's experiences around social participation were unique. In response to Sara and Lou-Lou's comments, she stated, "I have never felt like that. We have had just the opposite. Of course, Joe is my son." Sue, Sara, and Lou-Lou acknowledged how their relationships to the stroke survivor may have impacted their levels of social participation after the stroke. Sue and Joe have continued to experience active social lives in part because their lives are more separate, which is typical for a mother and son. Sue described her son's social life stating, "He still has support from his friends that makes it

more fun for him and gives us all a break.” Sue also has family living nearby (including Joe’s daughter) to depend on for additional support.

Theme 3: Caregivers’ Emotional Well-Being was Challenged after Stroke

All of the participants emphasized the impact their family members’ strokes had on their emotional well-being. Although there was a general sense of pride and reward in being able to care for her loved one, each caregiver also explained situations that brought about negative or discouraging emotions. As well as coping with changes in their personal and social lives, caregivers experienced feelings of fear, worry, depression, and guilt. These feelings largely occurred shortly after the stroke, early in the rehabilitation process. The participants described feeling overwhelmed when their family members were released back into their care shortly after the stroke. Sara said that she was worried that the stroke would, “change him [Clarence] into a really depressive state.” Lou-Lou described her emotions when he husband was released from the nursing home. Although she was happy to have her husband home, she couldn’t quite describe how the circumstance made her feel, stating, “But when we got home and stuff, I mean, I was so, I don’t know if I was at that time depressed I was just so...” With encouragement and help from Sara, the two friends found the correct word to describe another emotion – fear. Lou-Lou explained, “Scared. I couldn’t even look at my husband without crying.”

Some of these feelings of fear and guilt continue to this day. When discussing her thoughts about leaving her husband alone, Sara described a specific feeling of fear, “Is he going to get his meds right? What if he doesn’t eat all his lunch, then is his blood sugar going to drop?” Due to her feelings of fear that something could go wrong, Sara has never spent a night away from her husband since his stroke. Lou-Lou, who has spent one

night away from home since her husband's stroke, expressed similar feelings. She noted that she would feel guilty if she were to leave her husband for an extended period of time. Sue explained her situation differently as she cares for her son and has a great deal of family support nearby. She and her son, Joe, qualify for the COPES program, which pays for personal care and other services. Sue has been able to leave her son numerous times, at one point for a month, and has not experienced feelings of guilt related to this as she knows he is well taken care of when she is not around.

Theme 4: Friendships Based on Shared Experiences

When asked to describe what the support group has meant to the participants, the word highlighted most by the participants was friendship. It has provided the caregivers with a social outlet with individuals who had shared experiences regarding stroke and the subsequent rehabilitation process. Sara noted, "You don't feel so isolated." Sue said, "We are therapists for each other. We don't have to pay for it." The feelings of camaraderie were evident throughout the focus group – the participants were very talkative and made jokes with one another. Both Sara and Lou-Lou noted that maintaining friendships with other individuals was difficult. Sara said,

Because the simple fact is that other people just don't get it. We have talked so many times amongst ourselves about the stupidest things that people will say -- "Well, why don't you just do this?" And after awhile, you shut down. You start not talking about a certain issue or problem, because they don't understand. I mean, you can't expect them to get it. And so you find yourself being really guarded...I mean, it is really hard to verbalize this. You have got friends that would do anything to help you, but then they can't really get what it is you need.

This theme of friendship extended to the care receivers as well. During the focus group, they sat together in the waiting room. Lou-Lou noted that the care receivers "talk about everything." Sue commented that the stroke survivors had gotten to know each

other in the therapy gym, and, after therapy, “I could see that they kind of wanted to hang back. There was no hurry to get home.” The informal support group still gets together for lunch once a month, even though none of them are currently attending the on-site clinic. Because the stroke survivors are friends as well, it makes the informal support group more inclusive and, likely, easier for all to attend the regular lunches. The nature of the support group allows Sara and Clarence and Lou-Lou and Allen an opportunity to socialize as couples with others.

Sue expanded on the dynamic of the relationship among the informal support group, stating, “It was just easier to connect with some than others. We were all in the same position, all taking care of loved ones, and the four of us just hit it off!” Her son Joe’s friendship with Allen and Clarence contributed to the bond of friendship among the caregivers. Sara, who described herself as less of an extrovert, talked about how Sue and Lou-Lou connected with her. “These two are really friendly. I became better [more talkative] when I saw the benefit and the waiting room became fun.” Lou-Lou laughed as she confirmed, “We just sucked her right in!”

The informal support group even expanded at times to include other caregivers in the waiting room. Lou-Lou said:

The four of us, we would just kind of group in a little area, and then all of a sudden it wasn’t just the four of us anymore, and we would be talking back and forth to each other. I think it really helped the other people as well, because they wanted to tell their stories, and what has happened to them, and how it is for them to be a caregiver.

It is clear that the opportunity to share and connect with other caregivers was almost contagious. Not only is there a desire for social interaction, but for social interactions

with individuals who share some understanding of your life, role, and its joys and challenges.

Theme 5: Shared Information from Others in the Same Boat

The caregivers reported that the informal support group provided them and the care receivers with valuable information. Lou-Lou noted that her husband learned things from the other care receivers that she could not teach him. “And they learn so much from them -- they even learn how to put their braces on and stuff and how each other does it -- how each other gets dressed.” Lou-Lou also said that she learned more from Sue than from the formal support group she and her husband attended at one point:

When I got this lady here, I found out more information -- I mean, just from word of mouth things that she had gone through with Joe, and things that she had told me about, and stuff, to look this stuff up.

Shared information helped lead to some changes in the amount of burden that the caregivers experienced. Sara initially noted that she did not think the amount of burden she experienced as a caregiver had changed since participation in the informal support group, but she later stated that it did feel easier. Although perhaps the physical amount of work had not significantly changed, the participants noted that their attitudes had changed. The participants noted that burden may have decreased because the informal support group helped them to learn to let the stroke survivors do things for themselves.

Sara said:

If the burden has lessened...I think it has more to do with the caregivers learning how to back off when they realize that this person -- this patient, husband, son -- can do a lot more. It isn't about do they, it is about can they? And once I really got that, I really backed off.

All the participants noted that Sue really encouraged Sara and Lou-Lou to start backing off. She had pushed Joe to do more things on his own and, since he was farther along in

the rehabilitation process, they had seen the results of his work. While the burden has decreased somewhat or changed for the participants, it should be noted that only one of the three (Sue) said that she was able to leave the care receiver for a night or more without feelings of guilt or fear.

Theme 6: Social Comparisons Can be Helpful or Discouraging

According to the study participants, the stroke survivors of the informal support group have found that spending time with a stroke survivor who has made a lot of progress in his rehabilitation (specifically, Sue's son) is inspirational. Sara noted, "He is our hope" and Lou-Lou noted, "He offers his experience and expertise" to the other stroke survivors. It was positive for the caregivers to see an individual who was more independent post-stroke as it offered them hope for the future as well.

Downward social comparison with stroke survivors who had not progressed in rehabilitation was at times depressing to the caregivers and stroke survivors. Lou-Lou reported that one of the reasons she and her husband decided to stop attending a formal support group was that her husband, Allen, found it depressing to spend time with people who had not recovered well. This occurred early in the rehabilitation process for Allen, which may have contributed to why he found it depressing.

On the other hand, Sara cited downward social comparison as one reason that helped her have a positive outlook on her circumstances. She mentioned the saying, "You don't have to look very far to see someone worse off than yourself." She and her husband would see other stroke survivors or individuals with disabilities in hospitals, waiting rooms, or out in the community, and it helped her to realize that, in many regards, she and Clarence were lucky. Sue noted that Joe was lucky to be able to leave the skilled

nursing facility and come home. “Some of those people aren’t as lucky as our guys, really.” The word “lucky” was used by each participant throughout the focus group. It appeared that downward social comparison occurred throughout the rehabilitation process, and while it was not always uplifting, it may have contributed to the grateful attitude that the caregivers hold today. Cohn (2000) found similar results in her study. “This observation and downward social comparison process helped the participants reframe their perceptions of their children and helped them accept their situation” (p. 171). Morris and Morris (2012) also found that social comparisons could be either “uplifting or demoralising” (p. 353).

Discussion

Each caregiver in this study reflected on her experience with a family member who had a stroke that occurred between five and nine years ago. The three caregivers described the impact the stroke had on them in vivid terms, providing insight into the caregiver’s lived experience of caring for a stroke survivor. The participants described how the stroke changed their lives in terms of future planning and expectations, social participation, and emotional well-being. Each caregiver also expressed the significant value of their participation in an informal support group that evolved in the waiting room. This informal support group allowed them to share information, form lasting friendships, and compare themselves with others in situations similar to their own. Participation in the informal support group helped to meet some of their needs that arose as the participants became caregivers. It provided them with an opportunity for social participation and improved emotional well-being. The chance to share information and receive advice from others helped to decrease the amount of burden they experienced. The opportunity for

comparison with a stroke survivor who had progressed well in the rehabilitation process provided inspiration for caregivers and stroke survivors. Figure 1 depicts the relationship between the challenges of caregiving and the ways in which the informal support groups helped participants meet these challenges.

Previous research has found that caregivers often reduce their planning for the future and, in turn, focus on taking things one day at a time. In a study by Dowswell et al. (2000), one caregiver compared the loss of future plans to a balloon bursting, stating, “Everything’s gone. You know, all your plans, everything you were going to do!” (p. 510). A similar study conducted by Bulley et al. (2010) uncovered an emerging theme among caregivers as they described how future aspirations were put on hold, relaying a sense of loss in relation to hopes and plans. One caregiver stated, “Our lives changed 100 per cent [*sic*]. I’ve had to adapt to it, but it’s not what I envisaged my retirement being” (p. 1410). All three participants in the current study spoke of how this loss has forced them to adapt to their different expectations of life, specifically Sara, who explained how her and Clarence’s life changed from one that was more “flamboyant,” to a life of therapies two to three days per week. For many adults who look forward to retirement, the change in plans after an event such as a stroke can be devastating. Additionally, taking on a new role leads to changes in routine responsibilities and occupations, upending not only future plans but daily life. These changes can be significant adjustments for caregivers and care receivers.

Two of the three caregivers discussed how their lives now presented less opportunity for social participation and social interaction. A study conducted by Bulley et al. (2010) described a wife who was not able to get out and socialize with friends because

she could not leave her husband. “And then by the time you got it to this stage you’ve lost all your friends.” Research by Bolas et al. (2001) also supports findings from this study, as it highlighted recurring themes of emotional effects, such as depression, social isolation and reduced participation in life, and changes in role and workload in caregivers of stroke.

Participation in the informal support group addressed some of these changes in social engagement. Plans emerged out of the new friendships that formed in the waiting room. The participants got together for lunch on a regular basis. They were able to connect with friends who understood what they were going through, which two of the three participants had noted was lacking in their other friendships. Also, spending time with a caregiver and care receiver (Sue and Joe) who were further along in the rehabilitation process allowed the other participants to gain some inspiration for the future.

Sue offered a unique perspective regarding changes in social participation, as she is the caregiver for her son, not for a spouse. Neither Sue nor Joe experienced a significant decline in social participation after the stroke. Sue explained that her son’s close friends still take him to lunch and dinner, although she recognized that this is not the norm, stating, “Often the friends disappear.” Sue’s lack of a decline in social participation may be due to the fact that she and her son travel in separate social circles and spend time with friends of their own. Spouses quite frequently travel together, dine with other couples, and attend social events together. This may be one explanation as to why Lou-Lou and Sara have experienced a decline in social participation, whereas Sue

has not. She and her son have been able to maintain their own separate friendships, as they did prior to Joe's stroke.

The results of this study suggested that Sue's experience as a caregiver may be atypical. She often did not share the same experiences as Sara and Lou-Lou. Sue had more family support living close by, including a partner that she lives with, and her son, Joe, was the farthest post stroke. He does not require the use of a wheelchair, unlike Clarence and Allen. Joe's daughter plans on becoming the primary caregiver once Sue is no longer able to, and helps to provide respite care in the meantime. Sue and Joe also receive benefits from the COPES Program. Perhaps some of Sue's distinct experiences as a caregiver can also be attributed to the relationship that Sue has with Joe. The roles of mother and son are quite different from the roles of husband and wife. Sue frequently noted how caring for her son is different than caring for a spouse. Sue felt that even though children grow older, the parent is still the boss. Spouses, on the other hand, often view themselves as equals or partners. A study by Jones and Morris (2013) found that parents caring for an adult stroke survivor recognized the transition to caring as natural, whereas spouse carers experienced major and often difficult changes in their roles. Evidence suggests that the original relationship impacts the changes experienced by caregivers post stroke, and thus impacts the type of support needed. It is clear that, despite her unique situation, Sue still benefitted from the informal support group in many ways. She valued the friendships formed in the waiting room and it appeared that she enjoyed her role within the group, as a more experienced caregiver offering advice to newer caregivers.

Another theme that has been found in the previous literature and this current study relates to challenges to emotional well-being. In this study, participants commented about emotions of fear, worry, depression and guilt. A study by Smith, Lawrence, Kerr, Langhorne, and Kennedy (2003) found that caregivers of stroke survivors experienced similar emotions. Rodgers et al. (2007) found a high prevalence of stress in caregivers, with depression affecting up to half of the spouses of stroke survivors. These feelings and emotions make sense when considering the larger context around caregiving – the decrease in social participation, changes in long-term plans, and the often relentless nature of caring for a family member with a disability.

Previous literature has explored the value of formal support groups as a source of education, friendship, and social comparison (Morris & Morris, 2012). They can also provide caregivers and stroke survivors with a sense of community. Only one of the three caregivers interviewed had ever participated in a formal support group. Lou-Lou and her husband Allen attended about six sessions. As previously mentioned, Allen found that seeing stroke survivors who had not recovered well was depressing. Lou-Lou said:

I was kind of confused exactly what a support group was supposed to be in the beginning...I thought it was going to be kind of focused on the particular people and stuff, but it was more about getting information out to people.

However, while Lou-Lou and Allen did not like the formal support experience, they did meet a group of caregivers and stroke survivors that they still get together with on a regular basis.

Sara and her husband did not pursue formal support because a past experience, while their child was ill, left them with a dislike for this type of support. As she said, “It was not our cup of tea.” She also noted that she had heard negative things about one local

formal support group through friends, and that the one group that was recommended to her and her husband was led by a woman that they did not care for. Sara also noted that formal support groups take up time. It is not easy for her and her husband to just “jump in the car and go.” When asked about why she did not pursue a formal support group, Sue said that she received so much support from her family that she did not feel it would be necessary. “I felt I had all I needed in my family and didn’t need to reach out to community. Never felt it could be more helpful than the support I already had around me.”

The participants of this study were able to adjust remarkably well to the upheaval of stroke. The caregivers strongly expressed the value of the informal support group in their lives and the lives of the stroke survivors. The friendship and social support gained still plays a role in their lives today, five to nine years after the stroke occurred. Lou-Lou described its importance, stating, “It is therapy for us...it has helped me tremendously.” Sue explained, “You know...actually sitting down there, is therapy for all of us.”

If a caregiver has access to meaningful support, such as through an informal support group, it may enable him or her to continue providing care for a family member without experiencing burnout or psychological distress. Providing much-needed support to caregivers will likely increase the quality of life for both the caregiver and care receiver, potentially improving this relationship. Again, holistic treatment that considers the entire context surrounding the client is the responsibility of occupational therapists, and enhanced knowledge about this context will support client-centered and occupation-based interventions.

Implications for Occupational Therapy

The formation and role of informal support groups, whether for caregivers or care receivers, has not been a primary area of research in the field of occupational therapy. However, the results of this study indicate that informal support groups may uniquely meet the needs of many caregivers and care receivers. The three participants of this study either did not like formal support groups or were disinclined to try them. This has implications not only for occupational therapy but other fields of rehabilitative medicine as well. Encouraging the formation of informal support groups in clinics, hospitals, and other various rehabilitation settings may assist caregivers in meeting other caregivers who are in similar situations. Waiting room connections may be facilitated by scheduling clients with similar diagnoses or challenges at the same time. Sara noted that the formation of the informal support group was encouraged by the similarities they all shared in ages and time since stroke. This idea has been supported in other research (Morris & Morris, 2012). Occupational therapists may consider introducing caregivers with similar circumstances to one another. This can assist in fostering new friendships or, at the very least, allow two caregivers to share information about products or strategies that have been successful within their lives.

Another important implication for occupational therapists is the idea of encouraging caregivers to wait in the waiting room, rather than attending therapy, at least for some sessions. The participants of the study noted that, while they were initially resistant to the idea, spending more time in the waiting room encouraged them to connect with other caregivers. Sue explained how spending time in the waiting room was very helpful in establishing discussions among caregivers and was the time in which they

exchanged information with each other. They realized the importance of taking this time for themselves. It may be helpful for occupational therapists to think critically about which sessions would be valuable for the caregiver to observe, and which would be less so. Sara noted that she felt comfortable spending more time in the waiting room because the student therapists provided her with summaries and updates after each session. She felt that she was able to receive the information she needed without observing each occupational or physical therapy session.

Therapists' knowledge about access in the local community in which they practice can be another way to support the formation of informal support groups. The informal support group of this study goes out to lunch about once a month, and they commented that it can be difficult to find restaurants that can accommodate two to three wheelchairs. Meetings of caregivers and their care receivers outside of the walls of the waiting room may be facilitated by the therapist's knowledge of supportive and accessible places to gather and eat. Also, knowledge of the local formal support groups and their respective cultures and focuses can be helpful to caregivers and care receivers.

While scheduling clients and caregivers with similarities at the same time may facilitate the formation of informal support groups, another option can be to pair "veteran" stroke survivors with new stroke survivors. The findings of a study by Cameron et al. (2013) indicated that the needs of the caregiver change across the rehabilitation continuum, calling for varying types of support. Caregivers and stroke survivors who have already moved through the early stages of the rehabilitation process may have valuable information to share with those who are just getting started. Sue and her son had access to the COPES program and were slightly "ahead" of the others in the

rehabilitation process, and thus were able to offer advice to the other group members.

Sara mentioned another stroke survivor and caregiver she and her husband had met at the dog park:

Anyway, they just chat right along. They were both in the Air Force. They are both the same age. But what I notice is the other fellow -- now this just happened to him like a year and a half ago, so he is constantly pumping Clarence with questions about where was the best place to go for this, and how did you find out that...but for Clarence to visit with this gentleman, it has been good.

Clarence enjoyed sharing his expertise with a more recent stroke survivor. They shared similarities in age and profession, which perhaps provided them with enough common ground to form a friendship.

Lou-Lou's experiences with the formal support group and the informal support group indicate a need to pay attention to the timing of information and support. She noted that part of the reason she disliked the formal support group was because it was too early for her to take in all of the information that was provided. Her husband had just had his stroke when they went to the formal support group, and at that point she did not believe that any of the information really related to her. Lou-Lou noted that when she met Sue, she was able to ask questions and receive information as she needed it, rather than all at once. In addition, all of the participants noted increased feelings of fear immediately after the stroke. This change in emotions impacts an individual's ability to learn and remember new information. It is important for occupational therapists to keep this in mind as they provide information to caregivers.

The information that Lou-Lou provided about her experiences with a formal support group can provide occupational therapists and other healthcare professionals with some ideas for re-structuring formal support groups to better meet caregiver and care

receiver needs. Perhaps breaking up the support group based on each individual's stage in the rehabilitation process would encourage sharing of relevant and appropriate information. Breaking the group into caregivers and care receivers may also allow for more individualized attention and could encourage friendships to form based on shared experiences. Being more explicit about the focus of formal support groups could also be helpful to participants. Is the group focused on providing information and resources or is it a place where participants can blow off steam and share their experiences with others? Clarifying the intent of the support group may help participants choose a group that best fits their individual needs.

Limitations

The researchers initially planned to observe the study participants in the on-site clinic waiting room in order to introduce triangulation of data and increase the trustworthiness of the study. However, waiting room observations were not conducted because the participants' care receivers did not attend the spring 2014 occupational therapy clinic. The care receivers were placed on the waiting list for occupational therapy services and therefore were not available to be observed in the waiting room. This caused one of the four participants who had initially provided verbal consent to drop out of the study, citing the commute as too far. Another limitation was the small and relatively homogeneous sample size. The participants all identified as Caucasian and their family members have had access to occupational therapy and physical therapy since the stroke. None of the stroke survivors had significant aphasia or personality changes. The caregiving experience may be quite different for individuals of different races or

individuals who have had limited access to rehabilitation specialists. The results of the study may not be generalizable to all caregivers.

Future Research

Future research regarding the role and formation of informal support groups across the United States would be valuable, as well as further research about the particular group investigated in this study. Observing Lou-Lou, Sue, and Sara in the waiting room as well as during a lunch date with their family members would add depth to the data collected in this study. Future studies should also include the stroke survivors or care receivers as participants in order to better understand their role in the formation of the support group and how it has impacted their lives and recovery.

This study also brought up the need for more research about the effectiveness of formal support groups. How many people, like Lou-Lou or Sara, either seek out formal support but find that it doesn't meet their needs or are uninterested in seeking this support due to negative past experiences? Much of the research that was found in preparation for this study was conducted outside of the U.S., further highlighting the need for research here that can be generalized to American caregivers and care receivers.

The contrasts between Sue's experience of caring for her son and Lou-Lou and Sara's experiences of caring for their husbands also revealed an area for potential future research. Research regarding caring for a spouse versus caring for a child could provide insight into how this relationship affects the caregiver experience and the rehabilitation process.

Conclusions

The results of this study bring insight into how waiting room connections may influence caregivers. Participation in informal support groups may positively affect the caregivers' (and care receivers') well-being and quality of life. Certain themes emerged from the data regarding the caregiver experience of life after stroke, which included: 1) Daily Life and Future Plans Were Altered, Disrupted, or Lost, 2) Friends Wanted to Help But Rarely Understood, and 3) Caregivers' Emotional Well-Being was Challenged after Stroke. These themes appear to be consistent with literature from previous studies that focused on caregivers of stroke survivors and the concept of caregiver burden.

Additional themes emerged regarding the role of informal support groups, which included: 4) Friendships Based on Shared Experiences, 5) Shared Information from Others in the Same Boat, and 6) Social Comparisons Can be Helpful or Discouraging. Although little research exists on the formation and role of informal support groups, these themes appear to be consistent with literature from previous studies on the perceived benefits of formal support groups for caregivers and stroke survivors.

The findings in this study provide insight into the lived experiences of caregivers of stroke survivors, and further illuminate how connections and friendships formed in the waiting room of an on-campus, occupational and physical therapy student clinic may influence caregivers. These results may provide occupational therapists and other healthcare professionals with the knowledge and tools to better address the entire context surrounding stroke – not only the stroke survivor him/herself but the caregiver as well. The role of caregiving is critical in the rehabilitation process and can be incredibly valuable in itself. Successfully caring for a loved one and seeing their progress after a

significant injury can be a source of pride, joy, and can enhance the connections and relationship between caregiver and care receiver. Informal support groups may be a piece of the puzzle and provide the support individuals need as they embark on the journey of caregiving.

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Appendix

Focus Group Questions

The student investigators will begin with an overview of the study and interview questions:

Thank you for participating in this study. Through this focus group, we are hoping to gain a better understanding of your experience of being a caregiver for a stroke survivor. We are interested in learning more about your experiences in the waiting room of the University of Puget Sound clinic, as well as your experiences with both formal and informal support groups. We have some questions prepared, but this is not a formal interview so feel free to follow the natural flow of the conversation. We want to see where the conversation takes us! To start off, I'd like to spend just a few minutes hearing about your lives since the stroke. Both Beth and I will be taking notes throughout the focus group.

Experience of Caregiving:

- How has your life changed since the stroke?
- How has your health (physical and mental) been affected by your partner's stroke and by your role as caregiver?
- What is the hardest thing about being a primary caregiver for a stroke survivor?

Support:

- Have you ever participated in a formal stroke support group? If so, could you describe it and the effects? If not, why not? Did you ever consider a formal support group?

- What kind of support do you receive now? E.g. from family, friends, community.

Waiting Room Experience:

- Could you describe some of your experiences in the waiting room?
- When did you first meet another caregiver in the waiting room? How did this interaction occur?
- Does the dynamic of the waiting room change as people come and go? E.g., are your conversations different when there are more or less people present in the waiting room?
- How would you describe your relationships with the other caregivers you have met in the waiting room?
- Have you met other caregivers of stroke survivors elsewhere in the community? If so, could you describe the meeting and the relationship?
- Has meeting other caregivers of stroke survivors affected your life? If yes, how so?
- Have there been any changes to the amount of burden that you feel as a caregiver since participating in this informal support group?
- Do you spend time with the other caregivers you have met and their spouses or family members who had a stroke? Does this change the group dynamic? How so?

- Have any other individuals expressed interest in participating in the informal support group? Or just come and joined in the conversation informally?
- Do you find that the physical space of the waiting room affects your ability to connect with other caregivers?
- How does your experience in this waiting room compare to that of the previous one (before Weyerhaeuser Hall was built)? [This question will only be applicable if the participant spent time in the clinic waiting room before 2011.]

Table 1

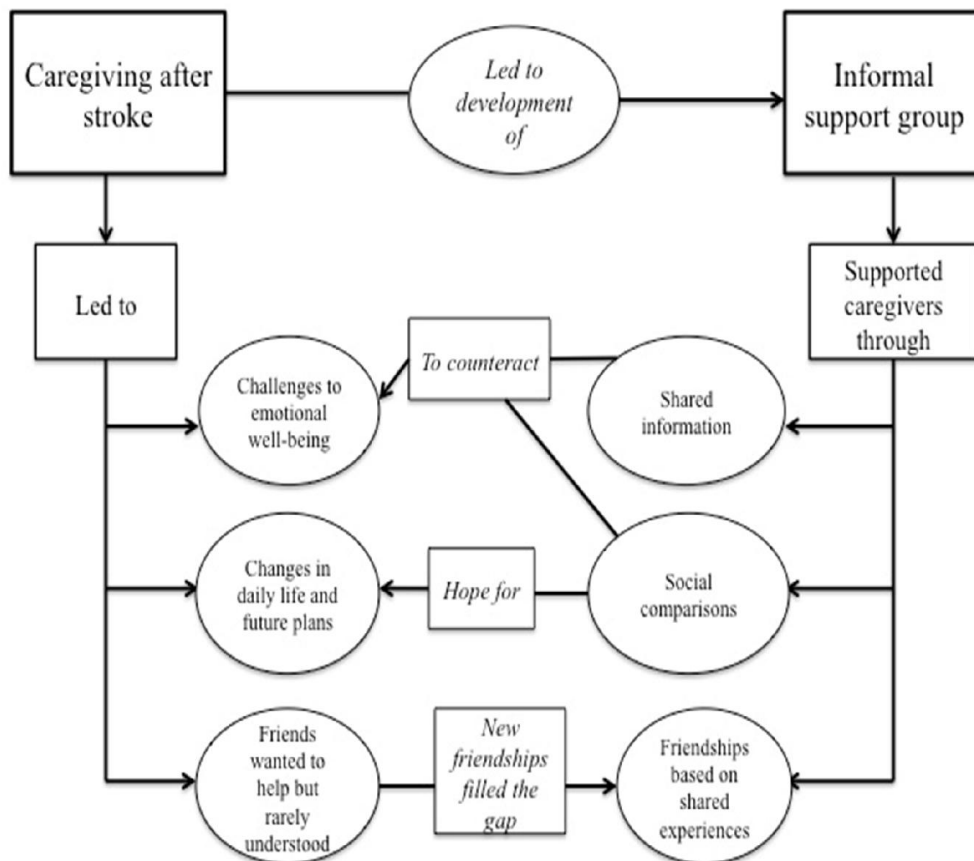
Summary of Caregivers and Care Receivers

| <u>Caregivers</u> | | <u>Care Receivers</u> | | |
|-------------------|-----|-----------------------|-----|----------------|
| Name ^a | Age | Name ^a | Age | Relationship |
| Sara | 69 | Clarence | 70 | Spouses |
| Lou-Lou | 65 | Allen | 65 | Spouses |
| Sue | 72 | Joe | 54 | Mother and son |

^aPseudonyms were used in place of participants' real names to protect confidentiality

Figure 1

The Caregiving Experience and the Role of Informal Support Groups



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