UNIVERSITY OF CINCINNATI

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I, Erin M Kibler, hereby submit this original work as part of the requirements for the degree of:

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It is entitled:

An exploration of family members' perceptions of communication/stroke support groups

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Caregivers’ Perceived Function of Stroke Support Groups in the Greater Cincinnati Metropolitan Area

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Master of Arts

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by

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B.A. Denison University, 2003

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Abstract

The purpose of this phenomenological qualitative study was to explore why family member caregivers of stroke survivors with a variety neurogenic communication disorders assimilated into their loved one’s stroke support group and continued to participate on a regular basis. Phenomenological research allowed the researchers to explore the caregivers' lived experiences and thus identify themes based upon their perceptions and opinions. Research studies describing the phenomenon of caregiver assimilation and why caregivers are actively involved in the stroke survivors' group were not found. Instead, many research studies have focused upon the social and emotional benefits of support groups for caregivers and support groups for survivors of neurogenic incidents. Caregivers of stroke survivors with a neurogenic communication disorder from different social, economic, and cultural backgrounds participated in semi-structured interviews in order for the researcher to understand their lived experience of participation in their loved ones' stroke support group. The findings suggest that caregivers joined these support groups for a variety of reasons including the goals of learning communication strategies to improve their interactions with the stroke survivors, discovering resources available in the local community and around the country, counteracting the lack of information received upon medical discharge, and the development of social support gleaned from other caregivers present in the group.
Acknowledgements and Dedication

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Finally, thank you to all of my friends, especially Leann, Kim, and Mandy who listened to me practice presentations about this project, complain during the writing process, and for understanding my schedule. My friends, I am finished, let the good times roll!

I dedicate this thesis to my husband Ethan for never holding me back and always reminding me that "this is your chance." My Mom and Dad because they have allowed me the freedom to find my own path, even though it took ten years and a few universities to figure it out. Thank you Mom and Dad for always understanding and supporting me throughout my adventures. I further dedicate this thesis to my sister Natalie for writing a thesis first and motivating me to want to do one too, and for always taking time to edit my writing. At least one of us learned how to write well.

Lastly, I dedicate this thesis to my Grandma. Although I never met you and no one had the opportunity or privilege of being your caregiver following your deadly stroke, I know you are always watching over me and leading me along this path of helping others. Finally, I dedicate this thesis to all of the caregivers and stroke survivors who are always finding a way to create lemonade and even lemon crème pie from life's lemons. There is always a way to conquer, achieve, and make life better.
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Caregivers’ Perceived Function of Stroke Support Groups in the Greater Cincinnati Metropolitan Area

Erin M. Kibler

CHAPTER I

Motivation

"...it feels like being in a dark hole where there are no doors or windows to open."

These words from the caregiver of a stroke survivor remind us of the adverse impact that a stroke can have on the social and emotional wellbeing of the family and friends of stroke survivors (Larson, et al., 2008). These words also illustrate that caregivers may not know what to do in order to help their loved ones overcome the medical, physical, and communication barriers caused by their stroke. Over time, the caregiving burden contributes to physical, psychological, and social stress, which can lead to elevated levels of depression, anxiety, hopelessness, and feelings of social isolation (Blonder, Langer, Pettigrew, & Garrity, 2007). Due to the sudden nature of a stroke, caregivers do not have the opportunity to prepare for providing fulltime care for their medically fragile stroke survivor; instead, caregivers' stumble through their new daily routine, while trying to maintain employment, leisure activities, and relationships.

Prior to hospital discharge, nursing staff may provide the caregiver with educational information about caring for their loved one’s medical needs in order to help ease the caregiving burden (Arts, Francke, & Hutten, 2000; Pringle, Hanedry, & McLafferty, 2008). Typically, information provided during the discharge process includes information about stroke, and the emotional, physical, and social barriers caused by the aftereffects of the stroke. However, the
information may quickly become irrelevant as the caregiver struggles to keep pace with the day-to-day caregiving responsibilities and the intensity of the first phases of rehabilitation.

As the caregivers and their loved ones establish their new routines, they may experience challenges finding information to help foster communication between the stroke survivors and extended family and friends (Lilley, 2003; Rodgers, Francis, Brittain, & Robinson, 2007). As one caregiver, who participated in the current study said, "a lot of people will tolerate folks that have certain disabilities, they don't tolerate speech, (and) the first thing that goes in your world is your social life."

Researchers have noted the importance of caregiver education regarding the stroke survivor's diagnosis (i.e., how to care for their loved one and facilitate communication); however, for this information to be useful, it must be provided at a time when the caregiver is ready to process the information (Blonder, et al., 2007; Draper & Brocklehurst, 2007; Rodgers et al., 2007). Perhaps, at the time of discharge, the caregiver is distracted by their loved one's medical status and physical needs (e.g., transferring in and out of the car, going to the bathroom, etc.) and is not able to attend to information that pertains to facilitating communication. The experience of some emotions such as hope, surprise, fear, worry, and sadness are accompanied by a feeling of uncertainty causing the caregiver to not understand what is happening, and feeling unsure about what will happen next (Tiedens & Linton, 2001). Additionally, the stroke survivor's needs constantly change during the first few months at home. Caregivers need information at a time when they are ready to focus on caregiving and the information must be relevant for a variety of caregiving situations, including their loved one’s current and future needs. Although caregivers receive information, they still struggle with the best way to help the stroke survivor to regain as high a level of functioning and independence as possible.
Communication Helps Achievement Together (CHAT)

In the summer of 2008, the University of Cincinnati recognized the importance of support groups in the chronic phase of stroke recovery by beginning the Communication Helps Achievement Together (CHAT) group. The CHAT group is a student-facilitated support group designed for people with a variety of neurogenic communication disorders (e.g., aphasia, dysarthria, cognitive-communication, etc.). The group meets weekly to provide people with neurogenic communication disorders a supportive environment to practice their communication skills and strategies with each other. Although caregiver education and support is not the focus of these meetings, the supervisor, and graduate student clinicians encourage the caregivers to observe the CHAT group.

Over a period of three academic quarters (approximately 9 months), the caregivers slowly became active participants of the CHAT group. Initially, caregivers lingered for a short period while dropping-off and picking-up their loved one. Over time, caregivers remained in the building, mingling with each other while their loved ones were in the CHAT group. Eventually they began to join the CHAT sessions - silently observing the activities. Over time, the caregivers placed their chairs around the table, next to their loved and one, and actively participated during the group session. The phenomenon befuddled and excited the group’s facilitators and we wondered, “what has changed or happened within the group to cause the caregivers to become more active and involved?”

General Statement of the Problem

A stroke can affect the well-being of both the caregiver and the stroke survivor. Due to the number of stroke support groups in the local community, it is clear that caregivers and stroke survivors attend, but the reason why caregivers assimilate into groups designed for the survivor
is unknown. One possible hypothesis is that, upon discharge from the hospital, caregivers do not receive the necessary information from their loved one’s medical providers. Another hypothesis is that caregivers do receive information however; they are not emotionally prepared to process the information at that time. Therefore, caregivers must independently seek this knowledge, later, when they are ready to move on to the next phase of caregiving. Stroke support groups may provide caregivers a mechanism to gather information to help them successfully care for their loved one. By attending these groups, caregivers also receive an opportunity to observe how other caregivers communicate with stroke survivors. Loss of communication can create a barrier between the caregiver and the stroke survivor, generating additional emotional stress for the caregiver. Involvement in a stroke support group helps to reduce the emotional stress and social isolation by providing an opportunity for caregivers to develop new friendships, redefine current relationships, and to receive realistic feedback about the life after stroke (Blonder et al., 2007; Shadden & Agan, 2004).

**Stroke Support Groups**

During conversations with the caregivers who participated in the CHAT group, the facilitators discovered that many also attended other stroke support groups throughout the Greater Cincinnati Area. According to the American Stroke Association, a stroke support group is, "A community organization for stroke survivors and their family members, friends and others, it helps people learn more about stroke, share their experiences about stroke, and become inspired to move forward after their stroke" (American Stroke Association, 2010). The CHAT group differs slightly from the American Stroke Association’s definition of a stroke support group because it is specifically designed for stroke survivors, rather than their family members. By attending a variety of stroke support groups, caregivers are able to gather information about
how to help the survivor regain skills, vent about the struggles of caregiving, and interact with caregivers who have endured similar experiences (Shadden & Agan, 2004).

Significance of the Problem

Approximately, 6.4 million Americans have a stroke each year (American Stroke Association, 2010). As more people continue to survive a stroke, the demand upon medical professionals to provide caregiver education will only increase. In fact, research indicates that adapting to life after stroke is not an immediate process, but rather a long-term commitment to recovery by the survivor and the caregiver (Draper & Brocklehurst, 2007; Rodgers et al., 2007). Caregivers are willing to do whatever they can to help the stroke survivor regain their independence; one way they can achieve this goal is by attending a stroke support group (hereto after referred to as support group) with their loved ones.

Purpose of the Study

The purpose of this phenomenological qualitative study was to explore why stroke survivor caregivers assimilated into the CHAT group and other local support groups designed for stroke survivors. Because caregivers frequently attend multiple stroke support groups, participants were recruited from multiple groups in the Greater Cincinnati Area.

The research addressed the following questions:

1. Why do caregivers become active participants in support groups designed for the stroke survivors?

2. How do caregivers learn about local support groups?

3. What is the perceived function of the various support groups within the Greater Cincinnati Area?
CHAPTER II

Review of the Literature

Literature regarding the caregivers' perceptions of support groups is sparse, as such, this literature review will summarize various components of the stroke recovery process, which can be linked together to help understand the caregivers' perceptions of the purpose of local support groups in the Greater Cincinnati Area. Specifically, research regarding the social and emotional impact of caregiving, needs of the caregiver, discharge process, and caregiver learning during discharge all may contribute to why caregivers' assimilate into support groups.

Social and Emotional Impact of Caregiving

Often, caregivers involuntarily take on the caregiving role without understanding the responsibilities of providing full-time care or, how caregiving will affect their own health and well-being. Because of the stroke experienced by their loved one, the caregiver often experiences negative social, emotional, and psychological effects (Draper & Brocklehurst, 2007; Blonder et al., 2007). Specifically, female spousal caregivers tend to have a lower quality of life following their loved ones' stroke, including increased psychological, physical, and emotional stress when compared to male spouses (Larson et al., 2006). With this consideration in mind, it is important for medical personnel to recognize how they can ease the female spouses into the caregiving role. For instance, they should receive relevant information specific to their needs in order to navigate the caregiving role successfully (Larson et al., 2006). However, male caregivers do experience emotional, social, and psychological distress because of their loved ones' stroke. Empirical investigations of caregiving for stroke survivors suggest negative outcomes including stress, depression, sleep disturbance, and diminished physical health (Blonder et al., 2007). Often times, the primary caregiver must leave his/her job in order to
provide care, or may have to continue working in order to provide insurance to cover the expense of rehabilitation and stroke-related medical care. In addition, caregivers may become socially isolated because they are reluctant to leave their loved one alone (Draper & Brocklehurst, 2007; Rodgers et al., 2007).

In an instant, caregivers experience immediate changes in their relationship with the stroke survivor; a concomitant communication disorder (e.g., aphasia) only exacerbates these changes (Draper & Brocklehurst, 2007). Furthermore, spousal caregivers of stroke survivors with aphasia tend to have a more negative opinion of their loved ones as compared to spousal caregivers of stroke survivors without aphasia (Zarick & Boone, 1991). In part, the negative opinions stem from the caregiver not understanding the diagnosis of aphasia. The caregiver only witnesses what their loved one is unable to do, and with aphasia, the loved one is unable to communicate as efficiently as they could prior to their stroke. This can create a barrier between the caregiver and the stroke survivor, and subsequently cause the caregiver to have lower expectations for their loved one’s stroke recovery. Caregiver education about aphasia may facilitate positive opinions regarding their loved one, and potentially have positive impact on their rehabilitation efforts.

Despite the evidence regarding the stress experienced by caregivers and their perceptions of their loved ones' abilities following discharge, little information exists regarding the caregivers' understanding of how a stroke impacts their loved ones' ability to communicate and participate in activities of daily living. Therefore, it is important for medical professionals to gage the caregivers' level of understanding of stroke prior to facilitating a personalized informational session. Providing caregivers with individually tailored post-stroke information may help them successfully care for their loved one and may potentially reduce the stress and
fatigue associated with full-time caregiving. Since the stress and fatigue associated with caregiving can negatively affect the rehabilitation of the stroke survivor (Bakas, Austin, Okonkwo, Lewis, & Chadwick, 2002; van Heugten, Visser-Meily, Post, & Lindeman, 2006), involvement in stroke support groups may actually speed the rehabilitation process. For example, support groups provide social support, which improves the caregivers' well being, as well as the opportunity to learn strategies to effectively communicate with their loved one and receive information about caregiving resources available in the community such as respite care, transportation, and medical supplies (Eldred & Sykes, 2008). Medical providers can provide this information during the discharge process and thus allow the caregiver to focus on caregiving instead of searching for local resources. Social support can begin in the hospital by healthcare providers sharing information and resources with the caregiver. Healthcare providers are not only the first responders to the stroke survivor's needs, but also to the needs of the caregiver (Eldred & Sykes, 2008) and therefore play a pivotal role in the success experienced by caregivers as they transition home with their loved one.

As the stroke survivor moves from the hospital to the home setting, caregivers should also be viewed as “patients” because of their need for information about how to care for the stroke survivor (van Heugten, et al., 2006, pp. 153). Many stroke survivor caregivers do not have a basic understanding of the definition of a stroke, much less the caregiving needs of a stroke survivor. Therefore, medical professionals must take time to educate and prepare caregivers for the challenges and responsibilities they will face when their loved one returns home. Because of the many cultural differences among families, it is nearly impossible to create a one-size-fits-all approach to preparing a family member to become a caregiver. However, it is important to recognize that a successful discharge is crucial to successful caregiving and the
long, arduous rehabilitation process. Unfortunately, the majority of education and discharge planning focuses on stroke survivors, instead of the stroke survivors and their caregivers (van Heugten, et al., 2006).

Regardless of the caregivers’ cultural background, caregivers want to receive information during the discharge process. African American and White female caregivers interviewed post discharge have expressed the need for information and strategies on how to manage behavioral and emotional problems (Bakas et al., 2002). Management of these problems can help to reduce the stress the caregiver experiences. In addition to tips about managing their loved one, caregivers also want to know more about medication management, transportation, and care during times the caregiver was unavailable (e.g., respite care). Caregivers frequently report feelings of disconnection between them and the medical professionals caring for the stroke survivor because they do not receive this information during the discharge process. As such, Bakas et al., (2002) suggest that the implementation of a “needs and concerns” checklist (pp. 245) and an informational handout, which includes caregiver strategies and tips, may facilitate positive interactions with caregivers during the discharge process.

**Dissemination of Information during Discharge**

Dissemination of information not only refers to when and how caregivers obtained information about how to care for their loved one, but it also includes the type of information health care professionals should provide caregivers prior to their loved ones’ discharge from the hospital. The discharge process has become a point of contention for many caregivers and their loved ones because communication breakdowns with medical professionals often occur at this point in the stroke survivors' medical journey. This communication breakdown prompts caregivers to participate in “seeking activities” (Brereton & Nolan 2002; pp. 24). Seeking is a
means for caregivers to discover information and gain knowledge. Frequently, caregivers report that they had to "go it alone" (pp. 24) and use outside resources, such as the Internet, to learn critical information not provided by the medical professionals (Brereton & Nolan, 2002).

Caregivers often report that they do not receive information critical to the care of their loved-one (e.g., community resources). Caregivers have reported a lack of information about stroke, treatment, community supports, and community resources (Eames, McKenna, Worrall, & Read, 2003). Lack of time or skills of the medical providers, or the unwillingness, or even the inability to attend to information provided (due to the stress of the newness of the situation) are just a few reasons why caregivers do not receive what they feel to be necessary caregiving information (Eames et al., 2003). Additionally, the information that caregivers may have received may be unclear, too complicated, or not specific enough to address issues relevant to the stroke survivor. Even the stroke survivors have reported dissatisfaction with information received. Tyson & Turner, 2000, found considerable dissatisfaction among the patients about the services they received during and after discharge, particularly the amount of information, support and therapy they received (Tyson & Turner, 2000). This is an important factor because this dissatisfaction contributes negatively to the social and emotional well being of the loved one. A frustrated loved one will be even more difficult for a caregiver to cope with.

Information sharing by healthcare professionals during the discharge process helps caregivers and stroke survivors participate in their care plan (Eames et al., 2003). During caregiver training, health care professionals should provide written information so the caregiver does not have to rely on recalling auditory information. This is especially helpful in the event the caregiver has a hearing loss or difficulty processing auditory information. Healthcare professionals should provide information using multiple modalities to insure comprehension and
application of the information following discharge. For example, instead of presenting caregivers solely with verbal information regarding care for the stroke survivor, medical staff should also provide augmentative written information (e.g., informational sheets or brochures). Written information allows the caregiver to pace their learning and to access the information at any time (Eames et al., 2003). Additionally, a combination of education and counseling is more effective than education alone for stroke survivor caregivers because it facilitates increased social and psychological adjustment for the stroke survivor (Evans, Matloc, Bishop, Stranahan, & Pederson, 1987). Ideally, caregiver education would include an informational session and a counseling session; this approach would increase the caregiving knowledge base and help caregivers cope with their new life situation (Eldred & Sykes, 2008).

**Caregiver Coping during Discharge**

In addition to counseling, healthcare providers may ease caregiving stress during the discharge process by employing a liaison nurse (Arts et al., 2000) or a caregiver-oriented discharge-planning program. Liaison nurses assists with the discharge process and, once patients are back in their home environment, assesses home care needs. The liaison nurse organizes home health services and medical supplies. Caregivers receiving liaison nurse services report decreased stress-levels during the transition into post-stroke life with their loved one. Caregiver-oriented discharge-planning programs are also successful in helping the caregiver transition home with their loved-one because they meet the needs of the individual caregiver. For example, a program conducted by research nurses included 4-5 in-hospital visits (Shyu, Chen, Chen, Wang, & Shao, 2008). During the visits, the research nurses provided verbal and written instructions and skills demonstration (e.g., transfers and hygiene care). Additionally, they conducted home visits to determine if changes to the home are necessary to accommodate the
stroke survivor (Shyu et al., 2008). This caregiver-oriented discharge-planning program emphasizes individualized health education and may help caregivers' transition home successfully after their loved ones’ stroke.

Despite the efforts of healthcare providers to support and educate caregivers during the discharge process, caregivers may be unable to process the information until much later in the recovery process. Caregivers experience a variety of emotions that affect their ability to attend to and learn the information presented during the discharge process; medical personnel must be cognizant of these factors.

The caregiver acquires many new responsibilities during the discharge process and researchers have questioned whether caregivers are able to absorb and retain information when health care professionals give information during the loved ones’ inpatient stay and during the discharge process. There are many explanations for caregivers forgetting information; the health care provider using difficult to understand medical terminology, information presented verbally, and the caregivers’ level of education and specific expectations can all affect the caregivers' ability to retain information and instructions (Kessels, 2003). Not only do these factors affect the ability of the caregiver to retain caregiving information and instructions, but the caregiver’s age can also affect his or her ability to retain information. The healthcare professionals provide facts that are labeled as episodic information and the encoding of this type of information can be impacted by age-related memory function (Kessels, 2003). Older caregivers may have a difficult time encoding verbal information provided by the health care professionals, especially when they do not receive augmentative visual supports such as a brochure to refer back to after discharge. Furthermore, older adults may also have more difficulty with their working memory and ability
to organize and encode the information they are provided and then structuring the information for later recall (Kessels, 2003).

During their loved ones’ inpatient stay, caregivers are undergoing emotional stress. Seeing their loved one in an ill state is a central detail the caregivers will have a difficult time not attending to or forgetting. When healthcare providers give information about the stroke survivor's prognosis and information about discharge, they are giving the caregiver peripheral details. Research has demonstrated that when a person undergoes an emotional experience, they are more likely to recall central details of that emotional experience instead of peripheral details (Wessel, Vander Kooy, & Merckelbach, 2000; Canli, Zhao, Brewer, Gabrieli, & Cahill, 2000). This means the caregiver will remember the central detail of their loved one being ill and not remember the peripheral details of what the doctor is telling them. This again supports the need to provide caregivers with additional augmentative information instead of healthcare providers relying solely upon verbal information. Once they have their loved ones home, caregivers may have many new challenges and questions about caregiving that they never imagined having to face while receiving discharge information. Attending the support groups, designed for the stroke survivor allows the caregiver to learn necessary information from professionals and other caregivers. The support groups also provide a new social outlet for caregivers in order to surround themselves with others who understand the responsibility of being a caregiver. Attending support groups provides a means to learn how to cope with the symptoms and deficits caused by their loved ones’ stroke and thus, help them become better caregivers.

Information from the field of audiology speaks well to the learning abilities of the caregiver during the discharge process. During the stroke survivors’ inpatient stay, bad news about the stroke survivor's prognosis contributes to the caregiver becoming distracted and unable
to retain and process subsequent details (Clark & English, 2004). During the loved ones' hospitalization, caregivers are faced with many facts related to what is wrong with their loved one and how their loved one is now different. Research, into the human brain has shown comprehension shuts down when a person is shocked or upset (Hobson, 1994; Sprenger, 1999). When caregivers block out details and information about the stroke survivors’ prognosis, they in turn impede the stroke survivors' rehabilitation.

Psychological demeanor affects how much information the medical staff shares with the caregivers (Braithwaite & McGown, 1993). In turn, this causes the medical staff to believe the caregiver is not ready to, or is unable to retain given information. In their study, Braithwaite and McGown found no evidence of emotional distress hindering caregivers in their quest for knowledge. There were limitations to their study because the caregivers sampled had already settled into the role of caregiving and these were not caregivers of loved ones currently hospitalized.

Success stories are a powerful tool to help stroke survivors to participate in the healing process and to understand themselves better (Holland, 2006). Often, these stories become known during aphasia groups by the stroke survivors own realization, or the group facilitator recognizing and sharing the stories. When caregivers are present, they have an opportunity to hear the stroke survivors' success stories and to gather strength and hope from the stroke survivors' ability to live with aphasia (Holland, 2006). Through these success stories, the caregiver can adjust to their caregiving role and the stroke survivors' new conditions. Some caregivers jointly own the aphasia with the stroke survivor (Holland, 2006). Evidence of ownership is evidenced through caregivers participating with the stroke survivor in stroke support groups, and even during interviews when caregivers talk about aphasia as "we," or "our
problem” (Holland, 2006). The interdependent relationship between the stroke survivor and their caregiver contributes to both of their successes in coping with aphasia (Holland, 2006).

By attending the support groups, caregivers are participating in a stress coping model. By attending the groups, caregivers can learn successful coping strategies to help alleviate the strain of caring for the stroke survivor. Group support provides the caregiver with confidence and knowledge in the care of the stroke survivor and the implementation of coping strategies including confronting, and seeking social support (Eldred & Sykes, 2008). Meeting and spending time with other caregivers and hearing their stories about caring strategies allows caregivers to confront their own caregiving fears and to gain knowledge and support from those around them. The outcome of the stress coping model reports that caregivers who use positive coping strategies have less psychiatric symptoms (Eldred & Sykes, 2008).

In summation, it is important for healthcare providers to recognize the emotional state of the caregiver as well as to recognize the wants and needs of the caregivers in order to provide caregiving information in an understandable and efficient means. Additionally, caregivers must recognize the fact that many unforeseen caregiving hurdles may occur during the first few months of caregiving. Therefore, providing more information in order to encompass care for a long duration (i.e. beyond six months) instead of for merely the short term would be the most beneficial for the caregivers.
CHAPTER III

Methods

Participants

The researcher recruited participants from support groups located in the Greater Cincinnati Area. The researcher contacted local support group leaders regarding distribution of flyers to their membership. All interested potential candidates were screened via a short telephone interview to assure that they were a caregiver for a person who participates in a support group for stroke. For the purposes of this study, a caregiver was defined as the person who held primary responsibility to oversee the stroke survivor's healthcare and activities of daily living. Participants included 10 caregivers of stroke survivors (6 females, 4 males; age range: 30 – 80 years; Mean = 53.2 years) (see Table 1 for participant demographic information). To protect the identity of the caregivers, the researcher assigned a pseudonym to each participant.

Table 1

Research Participants

<table>
<thead>
<tr>
<th>Caregiver</th>
<th>Caregiver's Age</th>
<th>Relationship</th>
<th>Survivor’s Age</th>
<th>Years Post Injury to Survivor</th>
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<td>Sister</td>
<td>42</td>
<td>7 years</td>
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<td>80</td>
<td>Wife</td>
<td>71</td>
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<td></td>
</tr>
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**Research Design**

The researcher employed a phenomenological qualitative research approach to explore caregivers' perceived functions of stroke support groups in the Greater Cincinnati Metropolitan Area. This phenomenological approach allowed the researcher to gain insight, “…into people's views of reality” (Maxwell & Satake, 2006, pp.257). The phenomenological research design allowed the caregivers to express fully their thoughts and opinions about stroke support groups. The researcher was able to deduce the caregiver's reasons for their perceptions about stroke support groups because the caregivers were able to give their thoughts and opinions freely, without of the restrictions of a survey.

**Research Materials**

This study used a semi-structured interview that included open-ended questions and probes, as a basis for the personal interviews (see Appendix for the questionnaire). A Marantz Professional Solid State Recorder (PMD660) was used to record the semi-structured interviews. The researcher uploaded the digital audio recordings to a password protected, firewall secure Dell Precision T7400 located in an entry controlled research laboratory. During the transcription process, the researcher used Audacity (version 1.2.6A) (Mazzoni, 2010), a free, on-line digital audio editor, to play each interview. The researcher used a standard legal notepad to record notes and observations during the interview as well as field notes following each interview and Microsoft Excel 2007 to organize the orthographic transcriptions.
Procedures

The Institutional Review Board (IRB) of the University of Cincinnati approved this study on May 21, 2009 (IRB # 09-05-18-03).

Data collection. Data collection took place in either the participants' home, at the University of Cincinnati Speech-Language and Hearing Clinic, or via the telephone. The student researcher conducted all interviews; however, the faculty research advisor participated in the first two interviews to provide guidance on conducting semi-structured interviews. The student researcher engaged the participants in a semi-structured interview and encouraged them to speak openly about their experiences with their loved one, challenges as caregivers, and how they overcame those challenges. To facilitate conversation, the researcher asked participants open ended questions (Appendix), asked clarifying questions, and used elaborating probes (Creswell, 2005, pp.217). Additionally, the researcher observed and noted caregivers' non-verbal communication and the home/environment (during in-home interviews) in her field notes. Furthermore, the researcher documented themes revealed by the interview, in relation to other participants. This process facilitated ongoing analysis of the caregivers’ experiences regarding stroke support groups.

Data Analysis

Transcription. Prior to orthographic transcription, the researcher assigned each participant a pseudonym to ensure confidentiality. Although 10 caregivers participated in this study, only nine transcriptions were available for analysis due to technical difficulties. For this participant (Audrey), only field notes were available. The researcher orthographically transcribed the interviews. The transcriptions included all spoken exchanges of the researcher and the caregiver, as well as events during the interview, such as long pauses, laughter, and
interruptions. In addition, the researcher incorporated her field notes into each interview, highlighting relevant information relating to the research questions. All transcriptions were cross-checked for accuracy by another researcher.

**Preliminary exploratory analysis.** Two researchers (the student researcher and a trained research assistant) completed a hand analysis of the qualitative data. During the hand analysis process, the researcher read the data, recorded notes/observations, and divided the information into relevant themes relating to the research questions. Applying a preliminary exploratory analysis allowed the researcher to determine the lived experience of the caregivers. Each researcher conducted a preliminary reading through the data multiple times to gain a general sense of the interview as well as to analyze the comments of the caregiver relating to the research questions. During this process, the researchers added notes to the margins. Additionally, the student researcher reread and simultaneously analyzed her field notes to assist in developing a personal assessment of the data in relationship to the research questions. Throughout this process, researchers looked for overlapping themes across participants' interviews.

**Triangulation and coding.** Analyst triangulation validated the findings. After the researchers independently reviewed the data and applied coded labels to each interview, they compared their findings. The interviewer's questions and comments were not included in the coding. Details gleaned from the interviews during the coding process determined an overall picture relating to the research questions. To assure intercoder reliability, each researcher read the same eight interviews and color highlighted key text segments in the data in order to create broad categories based upon the caregivers' opinions.
The researchers' observations and personal assessment of the data in relation to the research questions created the broad categories. In vivo codes, codes stated in the participant's own words as well as codes expressed in the researchers own language based upon the researchers personal assessment of the information contributed to the creation of the broad categories. Overall, the researchers observed and then documented the repetition of key ideas and information that was similar among interviews in order to combine them into broad themes. Throughout this process, the researchers noted and developed the following types of themes: ordinary (i.e., expected responses), unexpected (i.e., information the researchers did not expect), hard-to-classify (i.e, ideas that overlap), major (i.e., major ideas relevant to the research questions) and minor themes (i.e., secondary ideas). The researchers eliminated redundant coded data and refined codes to include larger themes (Creswell, 2005).
CHAPTER IV

Results

Eight themes regarding caregiver perceptions of the Greater Cincinnati Metropolitan Area stroke support groups emerged during the analysis of the transcripts and researcher’s field notes. The themes highlight the reasons why caregivers became active participants in support groups, how they discovered local support groups, and their perceptions of the purposes of the stroke support groups in the Greater Cincinnati Metropolitan Area. The emergent themes included discharge, post-stroke support services, advocacy, group experience, information, student training, social (the friendships and emotional support caregivers received via participation), and moving forward beyond therapy.

Discharge

The discharge theme highlights the caregivers' experiences with medical staff prior to the stroke survivor returning to home and the lack of information received during these interactions. Caregivers conveyed that they did not receive information needed to assist properly in the care of their loved one. Refer to Table 2 for representative caregiver quotes.

Post-Stroke Support Services

The post-stroke support services theme reflected the lack of support from medical professionals and thus necessitated independent research by the caregivers to gain desired information. Refer to Table 3 for representative caregiver quotes.

Advocacy

The advocacy theme speaks to the tenacity and dedication of the caregivers who were willing to do anything they could to find the needed resources and help for the stroke survivor as well as to assist new caregivers. Refer to Table 4 for representative caregiver quotes.
Table 2

Discharge

Shelley: "...it is trial and error; you have to figure it out alone."

Mark: "...there was a tremendous disconnect between... the doctors and people dealing with you in the (hospital)......when you started working with therapists and the other doctors you ran into, there wasn't hardly any connection at all"

Kay: "... (I wonder if they) would...have given me those (pamphlets and practice exercises) if I hadn't asked for them. I don't know."

Jim: "...(The only thing) we got (was) a pamphlet in the hospital...there was nothing really available. There... wasn't anything all in one place."

Mark: "...they've (medical professionals) got it to where you're medically sound...but that's the beginning of a very long road here the work really begins and there’s nothing there."

Table 3

Post-Stroke Support Services Theme

Lisa: "(I wish someone would have told me)...Here (is what is available) in the community (and) what (I) can try."

Jim: "(I) looked at the Internet...We had to go find everything for ourselves."

Shelley: "I think it would...have been cool if...I was matched with (a caregiver mentor) to show me the ropes."

Shelley: "Early in the stroke, we were Internet junkies."
Table 4

Advocacy Theme

**Caregivers:**
Jim: "...(I) can remember how (I) felt when (the stroke) happened...(I want to) help people."

Lisa: "...somebody can learn something from us and our experience...knowledge is power."

Jim: "...you never give up, you never quit, you go on forever."

David: "...since we've been (going) there (stroke support group) so long, it's almost helping new people coming into the group (to learn from our experience)."

Pam: "...there's always other people who make suggestions and try to give hope."

Lisa: "...he (caregiver at a group) has all kinds of information...he really is a plethora of knowledge."

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**Group experience**

In the group experience theme, caregivers provided the reasons why they attend the stroke survivors' support group. Not only did caregivers recognize the benefits the stroke survivor was receiving from being with other stroke survivors, but the caregivers also discovered they were personally gaining emotional support, ideas, and establishing friendships. Refer to Table 5 for representative caregiver quotes.

**Information**

The information theme describes the information and resources caregivers obtained from group participation. This was information pertinent to the care and recovery of the stroke survivor. Refer to Table 6 for representative caregiver quotes.

**Student training**

Student training was a surprising theme because caregivers and the stroke survivors attend University sponsored/student clinician operated groups as a means to teach others about
strokes and to mentor future speech-language pathologists. Refer to Table 7 for representative caregiver quotes.

Social

Within the social theme, caregivers describe the social aspect they and their loved ones gain from group participation. This includes establishing and maintaining new friendships through group participation. Refer to Table 8 for representative caregiver quotes.

Table 5

Group Experience

Mark: "...right now, I go for both of us."

David: "...it's been...a Godsend."

Pam: "...It has been beneficial to make connections, to gain information, learn about resources in the community."

Kay: "...you find with the (other) caregivers what you're really searching for...."

Table 6

Information Theme

Shelley: "...we used the groups to make the contacts."

Mark: "...the purpose is to help educate you...make you aware of programs..."

Lisa: "...you can gain so much information (from) going to a support group."
Table 7

**Student Training Theme**

Mark: "...the main purpose (of the University groups) is...for their students to have a chance to interact with somebody (who is) aphasic."

Jim: "...the students) have been reading about (aphasia) in...books...but they have never seen (someone with it). (This gives them)...hands-on experience."

Tara: "...it's more than just a support group or a treatment group...it's an educational thing too."

Table 8

**Social Theme**

Lisa: "...after the meeting, caregivers hang around...to talk (about coping and communication strategies).

Mark: "...I look forward to the...chance to...interface with other people."

Jim: "...the first thing you realize is you are really not along after all."

Audrey: "...(it’s a) chance to see and be around other people who are sort of the same...an opportunity for her (stroke survivor) to go out and socialize."

Pam: "...just being around other people (stroke survivors) in the similar situation helps him realize that he’s not alone."

**Moving forward: beyond therapy**

The moving forward: beyond therapy theme describes the overall benefits caregivers perceive the stroke survivor receiving because of participating in stroke support groups. Refer to Table 9 for representative caregiver quotes.
Table 9

Moving Forward: Beyond Therapy Theme

Tara: "It has (helped) maintain his confidence."

Mark: "...if you work with it (recovery)...you can...move forward."

Kay: "...opportunities for him to practice his verbal skills, particularly with a caregiver."

Summary of the Results

Consideration of these eight themes speaks to the reasons caregivers became involved in support groups designed for stroke survivors. The discharge, post - stroke support services, advocacy, and social themes revealed that assimilation occurred because caregivers were looking for answers regarding how to communicate with and provide physical, social, and emotional care for their loved one. The group experience, information, student training, and moving forward: beyond therapy themes explain how caregivers discovered the stroke support groups in the Greater Cincinnati Metropolitan Area and furthermore, explain the caregivers’ perceptions of each group’s function. The caregivers reported that they gain different types of information from each group that is beneficial to their caregiving knowledge base. Each theme details the caregivers' insight regarding their experience with the different groups, especially, the networking that occurs among the caregivers at meetings. They use this time to share the different types of information that they can obtain by attending the various local groups. Caregivers report that they seek and participate in these groups because of lack of information and guidance they received during the hospital discharge process. In essence, they remain involved in multiple groups because of the social and emotional benefits (for them and their loved ones), the opportunity to “mentor” new caregivers, and because of the different types of information they are able to learn about caring for, and supporting their loved one post-stroke.
CHAPTER V

Discussion

Analysis of the eight themes revealed that the discharge, information, advocacy, and social, themes were paramount to understanding why the caregivers assimilated into their loved ones’ stroke support groups, how caregivers discovered other groups within the Greater Cincinnati Metropolitan Area and why caregivers chose to actively participate in multiple groups.

Discharge

During the discharge process, healthcare providers need to take into account the caregivers’ adjustment to the stress they are facing in becoming a caregiver for a medically fragile loved one, and whether the caregiver is able to independently employ stress coping strategies throughout the process. As mentioned earlier, caregivers undergo stress and even depression due to caring for a loved one. Often, a lack of knowledge about how to provide care for their loved one contributes to this stress and the discharge process offers a good opportunity for healthcare providers to help caregivers develop these skills. Of the 10 caregivers who participated in this study, none mentioned having a single person who organized the dissemination of caregiving information during their loved ones’ hospital stay or during the discharge process. Instead, information came from a variety of sources and typically only when the caregiver requested the information.

Many of the caregivers reported a lack of necessary information on caring for the stroke survivor following discharge. This reflects the same findings reported in studies involving caregivers of cancer patients (Bakas et al., 2002). However, all of the participants in the current
study indicated information discovery and gathering was their main motivation for attending the stroke survivors' stroke support group.

Overall, the results of the study indicated caregivers need to receive general information about caring for the stroke survivor prior to discharge and information should be provided in a written form that the caregiver could refer to when they need the information (Bakas et al., 2002; Eames et al., 2003). In the current study, caregivers felt that providing information during the discharge process would have made the transition home and first few months of caregiving less stressful. During the first few months of discharge, caregivers are going through the adjustment phase of learning how to cope with the loss of their loved ones' previous skills and function and how to care adequately for their loved one. Caregivers tend to use a seeking activity during the stroke survivors' inpatient stay and during the discharge process (Brereton & Nolan, 2002). However, the seeking takes place independently of the medical events and typically entails the caregiver using the Internet or other caregivers as resources to answer care questions.

Although the current study did not delve into the caregivers' psychological state during discharge, especially since some caregivers' loved ones were more than five years post-stroke, caregivers consistently commented on the lack of information provided at discharge as a contributing factor to their stress. Although caregivers involved in this study mentioned a lack of information provided during the discharge process, the researchers did not survey local medical centers to determine the type of information they typically provided during the discharge process following a stroke. It is important to consider how learning occurs during times of extreme emotional distress. Although the current study did not specifically question caregivers regarding their emotional capacity during the stroke survivors' hospital stay, many caregivers reported a
feeling of not receiving the necessary information and support to provide appropriate care for their loved one. Future investigations should explore the caregivers’ emotional reactions and capacity to understand educational material during the hospitalization period immediately following the stroke (Bakas et al., 2002). Perhaps the support groups become such a critical source of information because the caregiver has had time to adjust to their new, post-stroke life.

**Information**

The key reason all 10 caregivers became involved in the stroke survivors' stroke support group was to find needed information that they did not receive upon discharge from the hospital. Caregivers learned about the different groups for stroke survivors within the Greater Cincinnati Metropolitan Area by word-of-mouth and flyers at their local hospitals. More recent caregivers, (i.e., those caring for loved ones around one year post-stroke), reported that the loved one’s speech-language pathologist informed them of certain groups. Many of the caregivers involved in this study attend more than one support group because they feel that gain different information from the each group. The caregivers who did not find out about these groups immediately following the survivors' stroke discovered the groups via the Internet, by meeting others who were already involved, or they knew someone who was involved in one of the groups. The listing of support group information on the Internet highlights the notion that caregivers view these groups as a critical resource for families stumbling through the recovery process.

All caregivers need a variety of information during the discharge phase to help with their adjustment (Evans et al., 1987) and therefore attend a variety of support groups. In order to find needed information, each caregiver turned to the Internet as a means to gather knowledge. The stroke support groups are a means for caregivers to meet other caregivers and obtain needed information. Caregivers turned to the Internet because they felt they were alone and had not
received information during discharge. In addition to the Internet, caregivers turned to different support groups in the Greater Cincinnati Area.

**Student groups.** During the course of coding the data, a surprising theme developed related to graduate student clinician operated groups. Both the caregivers and the stroke survivors participated in the University of Cincinnati (Cincinnati, Ohio) and Miami University (Oxford, Ohio) stroke support groups in order to give back to the students who facilitated these groups. The caregivers did not view these groups as a major source of information compared to other local groups; however, these groups provided an opportunity for the caregiver and the loved one to give something back to the community. The Miami University stroke support group, facilitated by speech-language pathology graduate students, provides a therapeutic environment supporting and encouraging communication. Similar to the CHAT group (see Chapter 1, pp. 3), clinicians at the Miami University group invite and encourage caregivers to participate in the group meeting one time per month during the academic year of September – May.

**Drake Center support group.** The monthly stroke support group held at the Drake Center is free and offers an opportunity for both caregivers and the stroke survivors to meet others who have gone through a similar experience and to receive information about caring for a stroke survivor. A registered nurse facilitates the group and guest speakers provide information ranging from current research studies to tips about filing for social security. Activities do not focus on facilitating communication for the stroke survivors, however, the stroke survivors have the opportunity to meet with and communicate with those going through a similar experience prior to and following the meeting.
The Aphasia Support Group held at Mercy Franciscan Hospital – Mount Airy. This group is free, meets weekly and is facilitated by a caregiver of a person with aphasia— and who is 20 years post stroke. Guest speakers provide information, but are not available as often as at the Drake stroke support group. Both caregivers and the stroke survivors attend and the focus of the group is to provide a welcoming environment for the stroke survivors to practice communicating. The group also meets at different restaurants in the community to provide further communication opportunities for the stroke survivors.

Involvement in the university groups provides caregivers and stroke survivors the opportunity to be teachers for speech-language pathology students; whereas the Aphasia Support Group held at Mercy Franciscan Hospital – Mount Airy provides social opportunities in a semi-structured environment. In contrast, the Drake group is an information-providing group because of the guest lecturers from different disciplines and the overall opportunity for caregivers to network with one another. According to Lisa, "...you can gain so much information by going to a support group." This is a concept almost all caregivers take part in and information seeking was especially prevalent for the caregivers of this study. By seeking information, caregivers are able to adjust, socially and emotionally, to their new roles (Brereton & Nolan, 2002; Evans et al., 1987).

Advocacy

In addition to seeking information about ways to help their loved ones, caregivers are also advocates for survivors to become involved in support groups when they have depleted their rehabilitation insurance resources, or when they experience dissatisfaction with the quality and quantity of therapy received (Dowswell, Dowswell, Lawler, Green, & Young, 2002). The caregivers' interviewed for this study demonstrated a strong desire to advocate for their loved
one; that is, despite what the medical community told them, the caregivers did not accept that the ‘recovery’ period was over at the end of the first year following the stroke. All 10 caregivers were college educated and therefore understood the power of knowledge. As a result, they refused to allow anything to hinder their loved one’s access to services, which may help them to regain skills. Six caregivers even enrolled their loved ones in residential treatment programs, which sometimes required cross-country, or international travel.

Although the caregivers originally sought these programs and groups for the benefit of their loved one, the caregivers also indicated that they became active participants in the groups and treatment programs. The caregivers felt that they gained valuable information and social support from other caregivers, which helped them to communicate more effectively with their loved one, and thus, become better caregivers. Furthermore, when caregivers witnessed the progress of the other stroke survivors during the meetings, they realized that there was still hope for their loved one, and that they are not alone in the caregiving process. Since caregivers who experience significant levels of stress or depression may negatively affect the rehabilitation of their loved one, these positive caregiving experiences may also positively influence the recovery of their loved one (Bakas et al., 2002; van Heugten et al., 2006).

Social

Caregivers participated in the stroke survivors' support groups for many reasons. The social theme directly highlights why caregivers' are active participants in the stroke survivors' support group. Often, caregivers became active participants because of the positive benefits their loved ones received from participating. They also report positive personal social benefits.

An important element of the social theme was that the groups provided an opportunity for caregivers to make connections with other caregivers who have similar experiences. Caregiving
is a stressful experience, especially when the stroke survivor has receptive or expressive communication impairment (Draper & Brocklehurst, 2007). By attending these different support groups, caregivers have the opportunity to learn strategies to communicate with their loved one, especially when attending the CHAT, Miami, and Mercy groups. Research has shown that family members and stroke survivors undergo positive psychosocial benefits during and after participation in communication groups (Elman & Bernstein-Ellis, 1999). In the current study, many of the caregivers indicated a feeling of initial hopelessness due to not knowing what the stroke survivor wanted or needed (due to their communication disorder); other feelings included shock, upset, and anger. However, these feelings subsided once the caregiver had the opportunity to learn more about the effects of the stroke and obtain caregiving tips from other caregivers at their loved one’s support group meetings. Attending the stroke survivors support group was a way for caregivers to access social support, which was critical to their well-being (Eldred & Sykes, 2008).

In addition, the caregivers gained satisfaction and hope by witnessing other caregivers and stroke survivors initiate social interactions with their loved one. Socially, the support group environment provided an atmosphere of understanding of the stroke survivors. For example, one caregiver mentioned attending a social function with his loved one following her stroke and how those who used to come up to socialize with her prior to the stroke, did not during this social occasion, "...people will tolerate folks that have certain disabilities, they don't tolerate speech (disorders)." According to Jim, when describing his wife's experience with the support groups, he said, "...the social aspect, I think, is the most thing they gain and as they get more relaxed they get better." Caregivers enjoy seeing their loved ones interacting with other caregivers and stroke survivors because it resembles the stroke survivors' pre-stroke activities. The stroke
survivors are able to bridge these experiences with their life outside of the group and therefore gain some sense of normalcy (Mosheim, 2008).

**Conclusions**

The caregivers of this study are highly motivated individuals who were willing to support their loved one’s return to their pre-stroke level of functioning by finding information, and seeking resources outside of the Greater Cincinnati Metropolitan Area to help their loved one. This study is important for speech-language pathologists (SLP) because they often organize and lead support groups. Especially given that the negative attitudes and emotions of the caregiver can adversely affect the recovery of the stroke survivor, SLPs must help caregivers ‘recover’ as well.

Speech-language pathologists who work in the acute care setting can be one of the first health professionals who educate caregivers about the communication difficulties they may face when returning home with their loved one. SLPs are well prepared to educate the caregiver and to provide tools and strategies to assist the caregiver post-discharge; however, they must remember to provide the information in a supplemental written form so that the caregiver may refer back to the information later. Additionally, SLPs can educate their fellow health professionals regarding different communication modalities and by creating materials that are appropriate for different levels of caregiver understanding. During the follow-up process, SLPs can facilitate the support groups, continue to monitor the communication needs of caregivers, and provide supportive information.

**Limitations of the Study**

The sample size for this study reflecting only the Greater Cincinnati Metropolitan Area and four different stroke support groups, Drake, CHAT, Miami, and Mercy is a limitation to the
study because the smaller size may not be reflective of the larger population of caregivers. Due to the limited geographical location, it is difficult to determine if the caregivers' perceptions are similar to those of caregiver who experience healthcare in other large metropolitan areas or smaller rural healthcare settings. Additionally, all caregivers were college educated and represented middle-to high socioeconomic status. Due to their educational and financial resources, the caregivers may be more assertive and have more resources to find caregiving information. Because stroke knows no social, economic, or racial boundaries, caregivers from different socioeconomic backgrounds may have different needs than those reported in this study. Finally, the cultural diversity of this group was limited to Caucasians and one African American participant. Future investigations would benefit from a larger, culturally, and geographically diverse population in order to determine if the themes discovered are reflective of the population in general. Despite the aforementioned limitations, these preliminary findings will be beneficial to SLPs and medical staff in the Greater Cincinnati Metropolitan Area.

Implications

This study highlights the importance of considering and involving the caregivers in stroke support groups. Data collected during interviews suggests that caregivers participate in these groups in order to learn communication strategies and obtain information to support their loved one. Knowledge of the caregivers' perceptions of communication-based group intervention may help clinicians to provide introductory education for the caregivers regarding their role when they join support groups.

It is important to survey and interview caregivers of stroke survivors from different cultural and socio-economic levels who do not already participate in support groups to determine their perceptions and definitions of a support group (e.g., for some people their family may
provide all the support they need). This information may help to contribute further knowledge about the dynamics of why caregivers become active participants in stroke support groups. Furthermore, investigations that explore the type of information provided to caregivers—and how healthcare providers disseminate that information—may help hospitals to develop a supportive discharge policy. This will ensure that caregivers receive information regarding community resources, information about their loved ones' diagnosis and prognosis, how to communicate with the stroke survivor who has aphasia, as well as a plan of care following discharge.

Additionally, it is important to explore and compare the educational information hospitals distribute to caregivers during their loved ones' inpatient stay and during the discharge process. Further knowledge of the type of information provided by hospitals may help further illustrate the caregivers' point of view of a lack of information from their medical providers during the inpatient and discharge phases. SLPs or other health professionals who facilitate groups will benefit from understanding the needs of the caregivers. For example, they can design their support groups to address the caregivers’ needs for communication strategies. It is also important to discover if there is a socio-economic relationship between participation in support groups. If a relationship does exist, then caregiver education will rely upon the medical professionals who care for the stroke survivor.

For future studies, it will be important to try to contact caregivers soon after discharge to discover what information they remember receiving during their loved ones' hospitalization as well as interviewing medical professionals to learn what information they provide during the discharge process. This is important in order to determine how much the emotional state of the caregiver influences their perceptions of the information they receive during their loved ones'
hospitalization and the discharge process. This will also allow for a thorough investigation of the
types of informative caregiving materials and information they receive during discharge.

Finally, this research suggests that caregivers are either not receiving necessary
information about caregiving from healthcare professionals or, they receive the information at an
emotionally vulnerable time, when they are unable to process it. Knowledge of the caregivers'
perceptions of stroke support groups will facilitate the efforts of clinicians within the Greater
Cincinnati Metropolitan Area to expand or develop support groups that target the needs of
caregivers. Furthermore, information from this study may help to provide healthcare providers
in the Greater Cincinnati Metropolitan Area with the evidence to implement thorough caregiver
education prior to, during, and following discharge. Providing caregivers with the necessary
tools to be successful will positively affect the stroke survivors' recovery and confidence (Draper
& Brocklehurst, 2007).
References

American Stroke Association. (2010). *Successful stroke support groups, our guide to organizing successful stroke support groups.* Available online:


of Medicine, 96, 219-222.


Miami University Stroke Group.


Stroke Support Group: Drake Center.


**GUIDING QUESTIONS FOR SEMI-STRUCTURED INTERVIEWS**

*NOTE: SUPPORT = this word will be substituted with the name of the participants’ individual support groups for the interview*

<table>
<thead>
<tr>
<th>Introductory Questions</th>
<th>Answers</th>
<th>Probes</th>
<th>Answers</th>
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<td>Your name:</td>
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<td>Your age:</td>
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<td>Who is your loved one you care for?</td>
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<td>What is your loved one's age?</td>
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<td>How old was your loved one when the insult/injury occurred?</td>
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<td>What is your loved one's diagnosis?</td>
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<td>How long have you been your loved one's caregiver?</td>
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<td>What support group do you and your loved one currently attend?</td>
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<td>Why do you attend this group?</td>
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<td>How did you find out about the SUPPORT group?</td>
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<td>Who referred you?</td>
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<td>How long have you attended the support group?</td>
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<td>How often?</td>
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<tr>
<td>How long has your loved one attended the SUPPORT group?</td>
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<td>How often?</td>
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<td>What was your impressions following your very first support group experience? (Did you know what to expect?)</td>
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<td>Wanted to return? Confused?</td>
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**Transition:**

**Defining the SUPPORT Group**

<table>
<thead>
<tr>
<th>What does the SUPPORT group mean to you?</th>
<th>What activities?</th>
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<tbody>
<tr>
<td>What is the purpose of the SUPPORT group?</td>
<td>Is this therapy?</td>
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<td></td>
<td>Is this a social club?</td>
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<td>Is this a safe place to leave your loved one while you run errands?</td>
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<td>Transition:</td>
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<tr>
<td>Your involvement in the SUPPORT group</td>
<td>Why do you attend the SUPPORT group?</td>
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<td>Why do you leave during the SUPPORT group meeting?</td>
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<td>What makes you stay during the SUPPORT group?</td>
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<td></td>
<td>Do you participate during the SUPPORT group session?</td>
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<tr>
<td>Transition:</td>
<td>Benefits of the SUPPORT group</td>
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<td></td>
<td>What do you feel you get out of the SUPPORT group?</td>
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<td></td>
<td>What do you feel your loved one gets from the SUPPORT group?</td>
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<td></td>
<td>What improvements have/do you see in your loved one?</td>
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<tr>
<td>Benefits of the SUPPORT group</td>
<td>Answers</td>
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<td>Have you seen behaviors/strategies carried over/transferred to home?</td>
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<tr>
<td>Transition:</td>
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<tr>
<td>Your opinions about the SUPPORT group</td>
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<td>How would you describe your feelings about the SUPPORT group?</td>
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<td>How do you feel while getting yourself or loved one ready for the group?</td>
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<tr>
<td>What makes you return to the SUPPORT group each week/session/quarter?</td>
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<tr>
<td>Who do you perceive to be the group's facilitator?</td>
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<tr>
<td>How do you think your loved one feels about the SUPPORT group?</td>
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<tr>
<td>Transition:</td>
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<tr>
<td>Sharing information about the</td>
<td></td>
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<tr>
<td><strong>SUPPORT group</strong></td>
<td><strong>Do you share your SUPPORT group experience with others?</strong></td>
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<td></td>
<td><strong>What do you and your loved one talk about on your way home after the SUPPORT group?</strong></td>
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<td><strong>If you didn't attend the SUPPORT group session, what does your loved one tell you about the SUPPORT group?</strong></td>
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<td><strong>Do you attend other groups similar to your SUPPORT group?</strong></td>
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<td></td>
<td><strong>Do you have any other information you would like to share that was not addressed during the interview?</strong></td>
</tr>
</tbody>
</table>