Questions Caregivers Asked in Caring for Persons with Stroke

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Citation:

Abstract

This secondary data analysis examined e-mailed questions asked by Midwestern caregivers of persons with stroke [n = 11 males; 25 females] who joined a web-based, support intervention for one year. The participants were primarily white spouses and, on average, age 54. Rigorous content analysis of 2,148 e-mail entries posted to the intervention’s discussion group or asked of the online nurse, resulted in five themes that were drawn to Friedemann’s framework of systematic organization. Themes of socializing with a group and asking questions about medical care emerged for all subjects. Female caregivers’ themes of dealing with change and validating caregiver efforts emanated. Specific to only the male caregivers, the theme of giving advice evolved. Nurses may use these themes as topics for interventions with stroke caregivers.

Key Words: Stroke, Caregivers, Survivors, Electronic Mail, Social Support
Introduction

Approximately 795,000 people experience a first time or recurrent stroke every year, making stroke one of the leading causes of disability in the United States (AHA, 2009). After an initial stroke, the average length of hospital stay is five days. Recovery from a stroke depends on its severity. Fifty to 70% of people with stroke regain functional independence, but some survivors are left with hemi-paresis (50%), need assistance to walk (30%), are dependant in activities of daily living (26%), experience aphasia (19%), and/or have depressive symptoms (35%) (AHA). Twenty-six percent of individuals with a stroke are cared for in nursing home settings (AHA); while most survivors are cared for by family members in the home (Berg, et al., 2005). Stroke impacts the individual as well as their families and friends who take on caregiving roles (Draper & Brocklehurst, 2007). Family caregivers experience life altering changes after stroke, as they must learn how to manage caregiving at home. Care for survivors may raise questions for family caregivers who often feel unprepared and overburdened.

Description of the Problem

Literature: Caregivers

Caregivers can become emotionally enmeshed in the caregiver experience and face negative consequences of disruption in family relationships, friendships, and personal activities (Mature Market Institute Metlife, 2003). Large numbers of caregivers must balance employment responsibilities with that of caregiving. Most caregivers are female and many of them are simultaneously caring for older relatives as well as raising children or grandchildren (AOA, 2007). In addition to being fathers, husbands and sons are also taking on the responsibility of caregiving. In fact, 40% of caregivers are male (NCA and AARP, 2005). In the last two decades, male caregivers are just as likely as females to report personal consequences in providing care (Chang, 1991; Long & Harris, 2000; Pierce & Steiner, 2004). In spite of this, male caregivers view caregiving as a form of work or tasks that need to be accomplished (Gandel, 2009).

More than 54% of caregivers in a study of 1,002 informal caregivers who helped with activities of daily living such as feeding, bathing, using the toilet, or lifting said that they received no formal instruction as to how to perform these tasks (Donelan et al., 2002). In a study by O’Connell, Baker, and Prosser (2003) using semi-structured
interviews, caregivers (n=28) were asked to talk about what their support and educational needs were in relation to the care that they were providing. Findings revealed that caregivers in the acute setting were generally more concerned about the immediate health status of the person with stroke and medical interventions required. Caregivers in the community setting were by and large more concerned about the long-term implications of the stroke, the continuing effect it would have on them, and information on available services (O’Connell, et al.).

In order to provide care, suitable education and guidance are needed for caregivers’ success. Technological delivery of healthcare to individuals is increasingly feasible due to the rise in use of the Internet which has an estimated 1,668,870,408 users worldwide (Miniwatts Marketing Group, 2009). Nurses and members of professional health care teams that include physicians, therapists, social workers, dietitians, pharmacists, etc. are using the Internet to help caregivers (Keaton et al., 2004; Marziali, 2006). The Internet, e-mail, and web sites are relatively quick and inexpensive ways to connect with caregivers and direct them to information to assist them in caring. Timeliness is one of the greatest advantages of web-based communication (Beauchamp, Irvine, Seeley, & Johnson, 2005; Glueckauf & Loomis, 2003; Damianakis, Climans, & Marziali, 2008; Marziali, 2006).

Keaton et al. (2004) reported on the role of an e-rehabilitation team in addressing caregivers’ concerns emailed to a nurse specialist as part of a web-based education and support intervention called Caring~Web©. These investigators shared how the rehabilitation team helped new caregivers of persons with stroke (n=13) in dealing with the effects of stroke by providing information on medication management; community and government services such as respite care and Medicare and Medicaid waiver programs; and stroke and related issues including physical well being of the person with stroke, as well as the care recipient’s and caregiver’s emotional well being (Keaton, et al.). In order to further study the information needs of caregivers, this project examines the questions caregivers emailed each other or the nurse specialist during their participation in Caring~Web.

**Conceptual Framework**

This project was guided by Friedemann’s (1995, 2009) framework of systemic organization. According to Friedemann, behavior patterns which strive toward congruence or balance that are acted out in daily life can be observed and organized into four process dimensions. These process dimensions are: system maintenance, coherence, individuation, and system change. System maintenance in caregiving situations involves the tasks of caring for the person with stroke and the organization of tasks like personal
care, time schedules, work assignments, communication patterns, and procurement of outside help.

Maintenance also involves those actions that caregivers undertake to maintain their own well-being, such as rest and sleep, social contacts, good nutrition, and recreation. Coherence signifies being at peace with oneself or feeling as one unified self. Coherence can be achieved by caregivers through a variety of actions that prevent anxiety, depression, exhaustion, or feelings of inadequacy leading to renewed energy and a positive attitude. Another process dimension is individuation, a process of self-development through learning, experiencing, and finding a purpose in one’s situation and life in general. Caregivers learn by giving care, exploring facts about stroke, interacting with others, or finding value in their caring. Individuation leads to system change as caregivers become conscious of the impact of their new responsibilities and make changes in their priorities, attitudes, and values and, as a result, assume new behavior patterns (Friedemann). For more information about Friedemann’s framework of systemic organization and a figure which illustrates her concepts, see http://www.fiu.edu/~friedemm/framework.htm.

**Purpose**

The purpose of this secondary data analysis project was to examine questions asked by new caregivers of persons with stroke who conversed via email. These data were from a web-based, intervention study on the experience of caring, referred to as the parent study hereafter. The parent study assessed the effects of the intervention on caregivers’ well-being, as well as problems and successes in caring, and care recipients’ use of healthcare services (Pierce, Steiner, Govoni, Thompson, & Friedemann, 2007; Pierce, Steiner, Khuder, Govoni, & Horn, 2009). The research question for this current project is: What questions do new caregivers of persons with stroke ask in the first year of caring at home while they participated in the web-based intervention? This project examined a research question not originally posed in the parent study.

**Methods**

*Caring~Web©*

The web-based intervention, Caring~Web©, was developed to provide in-home guidance for caregivers of persons with stroke and was used in the parent study from 2002 – 2005 (Pierce et al., 2009; Pierce et al., 2007; Steiner & Pierce, 2002). The site is now freely available at [http://caringweb.utoledo.edu/](http://caringweb.utoledo.edu/). Two components of the Caring~Web site include education and support (Steiner & Pierce).
The education component consists of linked education sites on a variety of topics related to stroke and caregiving. There are also links to greeting cards, games, and general world news. In addition, the site connects to news on diagnosis and pharmacological treatment, primary and secondary prevention, risk assessment and screening, and rehabilitation related to stroke. Short customized tips for caregivers in a problem/solution format are also available on stroke topics of interest such as nutrition, pain, and stress management; exercise; and safe transfer techniques (Steiner & Pierce, 2002).

The support component enables caregivers to interact with other caregivers and a nurse specialist who may consult with other rehabilitation professionals via e-mail. Caretalk is a discussion group which connects caregivers to other participants and Ask the Nurse enables the caregivers to ask the nurse specialist more personal question regarding caring for the person with stroke. These resources provide caregivers quick answers to common problems encountered during that person’s rehabilitation process (Steiner & Pierce, 2002).

**Design, Participants, and Data Collection**

After Institutional Review Board approval, a total of 144 caregivers of persons with stroke from four rehabilitation centers were screened for the parent study from May 2002 to December 2004 (Pierce, et al., 2009; Pierce, et al., 2007). These potential subjects were the primary person (≥ age 21) responsible for providing day-to-day care for a person with a first-time stroke who completed treatment and was discharged home in northern Ohio or southern Michigan. In addition, the caregiver was required to read, write, and understand English and be a novice Internet user. One hundred three caregivers met the inclusion criteria and were enrolled in the parent study. Caregivers were randomized to either a web user or non-web user group. Thirty subjects, divided equally between these two groups, did not complete this study. Reasons for non-completion included: some subjects moved; others placed the care recipient in a nursing home facility or the person with stroke died; and a few subjects were removed by the investigators for lack of participation in the intervention or interview process. The remaining 73 subjects (36 web users and 37 non-web users) completed the 1-year parent study (Pierce, et al., 2009; Pierce, et al., 2007). For this secondary data analysis project, a qualitative descriptive design was used in examining e-mailed asked questions of the 36 web users who participated in the Caretalk and Ask the Nurse components of Caring~Web and completed the 1-year parent study.

Norwood’s (2000) approach to data analysis was spearheaded by the doctorally prepared authors who have education and experience in qualitative research methods. The qualitative data analysis was done in three phases, deductive, inductive...
Entries containing questions were extracted and placed into categories relating to subject matter. **Within the data, patterns revealed differences or characteristics which were specific to one gender or the other. This resulted in theme identification that was either common to both genders or to male or female caregivers.** Themes emerged and were reviewed by all authors, as members of the research team, until agreement was achieved. Using Friedemann’s (1995, 2009) systematic framework, the themes were drawn to the framework in the integrative phase to bring meaning to them. With over 2,100 entries analyzed, these data were saturated and expanded the knowledge about questions asked by caregivers during their first year of caregiving. Since the authors were involved in content clarification, refinement, and consensus, the data interpretation is strengthened and further enhances the trustworthiness of the findings.

**Results**

**Participants**

Thirty-six subjects were new caregivers of a person with stroke, participating in Caring-Web during the 1-year parent study (see Table 1). The majority of these participants were females (69%). Their mean age was 54 years and the majority of them were wives (42%). They were also primarily White, not of Hispanic origin (86%). The majority of participants had at least a high school education (86%) and their mean years of schooling was 14 (SD = 3.9). Some participants wrote many e-mail entries to Caretalk and Ask the Nurse and others were less active in the discussions. There were 2,148 entries from participants (Pierce, et al., 2007; Pierce, et al., 2009) in which multiple questions were posed.

The care recipients (see Table 1 on next page) were mostly males (56%) and White, not of Hispanic origin (86%) (Pierce, et al., 2009). Their mean age was 63 years (SD = 15.0). The prevalence of chronic illness or co-morbidity was 67%.
Table 1.

Demographic profile of caregivers and care recipients (n=36).

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<thead>
<tr>
<th>Characteristics</th>
<th>Caregivers</th>
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<td></td>
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<td></td>
<td>41 – 50</td>
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<td>6</td>
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<td>51 – 60</td>
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<td>30.6</td>
<td>8</td>
<td>22.2</td>
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<tr>
<td></td>
<td>61 – 70</td>
<td>8</td>
<td>22.2</td>
<td>6</td>
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<td></td>
<td>Hispanic origin</td>
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<td></td>
<td>Graduate School (&gt;16)</td>
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<td>16.7</td>
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</tbody>
</table>

+ Caregiver's relationship data may be correlated to care recipient or the person with stroke.
++ Care recipient's education data were not collected.
In addition, the mean functional independence measure (FIM) score, an assessment tool to measure the ability to function (Uniform Data System for Medical Rehabilitation, 2009) at discharge from the rehabilitation centers, was 91 (SD = 14.9) (Pierce, et al.). Higher FIM scores indicate more functional ability or independence with a maximum score of 126 points to a minimum score of 18, representing dependence in all areas (Uniform Data System for Medical Rehabilitation).

Themes

Five themes emerged from the analysis of questions asked by new caregivers: 1) socializing in a group, 2) asking medical questions, 3) dealing with change, 4) validating caregiver efforts, and 5) giving advice. The first two themes were common to both male and female caregivers: socializing in a group and asking medical questions. The analysis found that an additional three themes arose that were gender specific. Themes exclusive to females were dealing with change and validating caregiver efforts. One theme restricted to males was giving advice.

The females’ entries were generally longer but were often vague. Their asked questions were most often embedded in entries sharing personal experiences and/or looking for mutual support. The males’ entries were more direct and typically sent as one sentence questions or in longer narratives when offering advice in the form of a question. Male caregivers asked questions that were often task oriented and more likely to be looking for a specific answer.

The following quotes are the caregivers’ words that illustrate these themes. However, the caregivers’ names are pseudonyms to protect their anonymity.

Theme 1: Socializing in a group (both male and female)

As the caregivers would turn to Caring~Web© for education and support, they developed unique friendships in its discussion components of Caretalk and Ask the Nurse. Many questions accompanied greetings of new members and asked about the caring situation of other caregivers and their care recipients. An example is:

Hi Cindy, I look forward to having you join our discussion, when and if you are ready? My husband had a stroke on March 30th of this year…. Whom are you caring for?
How are you holding up? We all know how difficult our journey has been, and can encourage and commiserate with you, as you wish?... Good luck.

Bonds formed and caregivers connected to one another. Throughout the year, caregivers sought support through ideas from the other participants and were genuinely concerned about their welfare and about the progress of their care recipient. Mark queried, “Sounds like you are going through a tough time [with the care recipient]? ... So hang in there. It is hard and don't feel badly about being tired or sad, it's all part of the game.” Betty shared, “I would like to thank everyone for their help through this year. It was nice to know there were other people with the same troubles. ...Anyone still want to chat on line? I'm at....”

**Theme 2: Asking medical questions (both male and female)**

These questions usually centered on asking about medical treatment, seeking information related to personal care, or asking for a specific answer for a targeted problem. A few examples of the questions are, “What are the chances of my wife having another stroke?” (Russ); and “What is a good way to overcome emotional stress?” and “What is a good antidepressant?” (Jeff). Others seemed to be looking for dates when recovery would be complete. For example, Jim asked, “[Therapy] progress has been slow, is it her or her therapy?” A month later Jim asked, “Isn’t it about time she is getting a little more pep?” Delores asked about her husband’s sensory deficit and this message serves as another exemplar.

What he wants to know is that the dullness in his touch (not knowing what he is touching when he is touching anything) will that come back all the way, some of the way, or stay disconnected? ...If something is in his hand without his eye sight he has no idea what it would be. Could this get better, come all the way back or is this forever?

**Theme 3: Dealing with change (female only)**

Since strokes can be severely debilitating and alter functioning, some female caregivers took on new roles and/or sought new strategies to deal with their loved ones needs. This theme emerged as the females expressed questions related to changes in day-to-day life. Margie asked, “[In the past] I have valued time to myself...but Lloyd’s new talkative personality... I get really desperate for peace and quiet. How do you handle togetherness vs. time alone...?”

Betty told about how she managed change in the following message.

Daniel has a way of giving you a look and shaking his head to let you
know you are not doing something the way he wants [like helping him eat or with paying bills]. This usually makes me feel like - why try? Nothing I do [now] is right, no matter how hard I try. How many times does he make me feel this way? More than I can remember. To feel better, sometimes I just cry or go for a walk to get away from him for awhile. Other times he will give me a hug and let me know he’s sorry. All in all, we are learning to deal with it [change].

These questions posed by the female caregivers centered on how to handle challenging new situations.

Theme 4: Validating caregiver efforts (female only)

The female caregivers used the web site to confirm their thoughts and feelings with other participants. This theme was expressed in several ways, generally after making a statement of fact, then reflecting upon that fact with uncertainty. For example, Sandy, when speaking about her husband not needing a medical procedure, stated, “… we are taking this as good news. Should we?”

The stroke survivors were often critical of their caregivers. Females wanted validation for the behaviors they developed to avoid criticism. Margie expressed this theme in the following post:

I think caring for Lloyd and never really knowing what is going to cause an impatient or critical response, makes me more tired than before…it is so hard emotionally to be on guard all the time, and to have to try to edit things. As a result, I seem to be more distracted…it seems as if my thinking is not as sharp, [is] anyone else feeling the same way?

From another group of responses, Judy said,

Your question of what makes me want to give up…. One minute he's [husband] as nice as can be and the next he's chewing on you and being totally mean and nasty! Isn’t that it? I've asked him, how he’d feel if I treated him that way? So of course he's very sorry, but give it a little time and he does it again! As far as fixing it goes, I've tried letting it go, I've tried talking about it, I've even gotten mad! Nothing works. I could use some suggestions here. What [do you] think?

In another exemplar, Sharon sought corroboration by asking whether she was
doing the right thing for her spouse. She said,

He is doing very well and only complained of being tired. I tell him not to push himself. He wants to do everything he did before in a hurry. Am I wrong to tell him to slow down and rest at times?

What can be derived from these statements is that the caregivers are asking, “Am I okay?” By expressing these questions to the group, female caregivers sought acceptance on a personal and emotional level.

**Theme 5: Giving advice (male only)**

The male caregivers frequently interjected advice through questions to all caregivers to help others improve their situation or resolve a particular issue. When Traci was discussing the lack of time off from work, Jim asked, “Have you tried to get some type of hardship leave?” When females were chatting about dealing with changes, like helping with dressing and bathing since the survivor’s stroke, Russ asked Edna the following question, “Would it help if you got one of your hubby’s friends that could sit and chat with him and casually bring up the changes that you have had to do to help him?”

By giving suggestions, caregivers were able to feel the value of what they learned from their role as caregiver. Mark offered advice to a fellow male caregiver:

…… She [wife] complained that people spoke too fast and she could not keep up. What if you made an audio recording of the sessions so she can listen later when she is not too tired, or also get some of her favorite passages read by members so she will have her own personal tape collection, finally, listening to praise music is soothing and provides another way of know the good words. Just some ideas.

**Discussion**

**Themes**

The themes of: 1) socializing in a group, 2) asking medical questions, 3) dealing with change, 4) validating caregiver efforts, and 5) giving advice were avenues in which the caregivers attempted to reestablish and maintain health. Drawing upon these themes, nurses can tailor interventions to provide care for all caregivers, as well as focus on
specific needs of female and male caregivers of persons with stroke. Table 2 displays the themes

Table 2.

<table>
<thead>
<tr>
<th>Male Themes</th>
<th>Female Themes</th>
<th>Process Dimensions</th>
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<tr>
<td>Socializing in a Group</td>
<td>Socializing in a Group</td>
<td>Coherence</td>
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<tr>
<td>Asking Medical Questions</td>
<td>Asking Medical Questions</td>
<td>System Maintenance</td>
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<td>System Maintenance</td>
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<td>Giving Advice</td>
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</tbody>
</table>

Theme 1. The theme socializing in a group is linked to the process dimension of coherence
(Friedemann, 1995, 2009). Within the web-based discussions these caregivers demonstrated
togetherness in that they formed emotional bonds and caring relationships among other group
members that has been described in other publications (O’Connell et al., 2003; Pierce, 2001;
Pierce, et al., 2007). Group socialization that consists of face-to-face or web-based interactions
with family, friends, spiritual advisors, or professionals or in support and educational settings needs
to be encouraged by nurses, because the caregivers in this project valued the opportunity to
socialize with others. This may help caregivers establish and/or maintain relationships. Male’s
direct style of communication may be a deterrent to others, so helping male caregivers to moderate
their interactions may be of value within group settings. Female caregivers, as members of groups,
may be encouraged to be more direct in their communication style in asking for what they need
from others.

Theme 2. The theme asking medical questions indicates a search for learning and self
development and is related to Friedemann’s (1995, 2009) process dimension
individuation. These caregivers responded to a crisis, the survivor’s stroke, and they needed new information to deal with the event, confirming O’Connell and associates’ (2003) findings that caregivers in the community were concerned about the continuing effect stroke would have on them as well as its long-term implications. In addition, this theme was portrayed within the process dimension of system maintenance, as the caregivers searched for stability and control. Caregivers reached out to others and asked medical questions to not only control the immediate circumstances, but to also plan for the future.

Nurses need to continually assess caregivers for lack of knowledge and provide one-on-one or group education and/or printed handouts to meet their educational needs. Nurses can also suggest the Internet as another vehicle for providing support through group discussions and information linked to valid and reliable web sites on various topics. For example, support and information is readily available from the American Stroke Association at [http://www.americanheart.org]; the National Stroke Association at [http://www.stroke.org]; the Stroke Network at [http://www.strokenetwork.org/]; or Caring~Web at the University of Toledo at [http://caringweb.utoledo.edu/]. Professionals can also develop iPod menus of articles related to specific needs that these stroke caregivers identified.

**Theme 3.** The female caregivers’ theme dealing with change is related to Friedemann’s (1995, 2009) process dimension of system maintenance. Similar to Donelan and associates’ (2002) findings, these females helped with activities of daily living in their new caregiving role. Dealing with changes reported by these female caregivers also focused on emotional adjustments, such as coping with personality changes of the person with stroke. While this may look like system change, true system change only happens over periods of time. In this first year of caring, these female caregivers were doing everything in their power to keep what they and the person with stroke had. They demonstrated behaviors grounded in tradition to preserve their lives or keep their system unchanged or channel information to produce desirable modifications to protect their lives.

Nurses during this time can assess the female caregiver’s adjustment to changes in her day-to-day life. Nurses can evaluate these caregivers’ coping styles and suggest ways to reduce stress by encouraging caregivers to seek help from others. Also, reminding caregivers to keep some sort of focus on self by finding the time to do the activities that they used to do may alleviate some of the burden that they perceive from their caregiving role. Females can be encouraged to discuss changes since becoming caregivers for persons with stroke with healthcare providers, as well as spiritual counselors or family members and friends.

**Theme 4.** The other theme that emerged specific to females was validating caregiver efforts and is associated with Friedemann’s (1995, 2009) process dimension of coherence.
These female caregivers explained the difficulties involved with providing daily care for their loved ones. They wrote, however, that the challenges were reachable and worth the effort for their loved one. Asking questions to confirm their ideas or suspicions helped the caregivers pull together and feel connected. Male caregivers potentially view the situation differently and perform different caring activities than females, and it may be hypothesized that males do not feel the need for validation (Pierce & Steiner, 2004).

When working with female caregivers either alone or in group settings, nurses need to confirm that the female’s feeling and behaviors are necessary and appropriate. These females also need to be allowed and encouraged to voice their struggles in caring, as well as justification for the work that they do for the person with stroke. These discussions may provide a valuable opportunity to corroborate their caring experiences.

**Theme 5.** The one totally male theme of giving advice depicted Friedemann’s (1995, 2009) process dimension of system maintenance and demonstrated that males become involved in caregiving activities, as suggested in the literature (Gandel, 2009; Mature Market Institute Metlife, 2003, NCA and AARP, 2005). As the male caregivers’ status quo was disrupted in caring, they freely shared information such as what worked for them, or told of assistance, like how to make the situation better or solve a specific issue to maintain stability and control. For males, helping both others male and female caregivers by providing advice may be something that they have always done and is a positive way that helped them to obtain balance, influencing the situation in a steady manner.

Nurses may capture and build on male caregivers’ direct style of communication and willingness to give information or assistance by involving them in general teaching, tutoring, or coaching sessions and/or in writing educational pamphlets or flyers for newer caregivers. Males could also be tapped by nurses to serve as partners to other caregivers providing face-to-face, telephone, or web-based assistance.

**Project Limitations and Strengths**

The results of this project may have limited transferability. The majority of caregivers in this sample were white Americans, residing in two Midwestern states, who used a web-based intervention. While data saturation was reached with a total of 2,148 entries, the results may not be transferable to all groups of caregivers of persons with stroke. Readers will need to make a decision if these results can be applied to their population of caregivers and in their setting. Future study can include more ethnically and geographically diverse groups of caregivers to examine their asked questions related to caring for persons.
with stroke. Nonetheless, strengths of the present project were that the caregivers participated for one year, ranged in age from mid 30s to 70s, and were new to the caregiving role.

The project's results indicate the need for nurses in all practice settings such as hospitals, clinics, homecare, etc. to listen for caregivers’ questions and concerns and provide answers and offer creative interventions. Nurses need to provide all caregivers of persons with stroke with opportunities to socialize in support and education group settings as well as to ask medical questions about the care of their loved one. Through assessment and intervention, they can help female caregivers deal with changes in their lives and validate that their feelings and behaviors are necessary and appropriate. Nurses can also involve male caregivers in teaching endeavors where they can give advice to other caregivers. Outside support is not always welcome; caregivers often refuse help and resources, as they may feel that professionals are prying into their private lives. However, effective intervention by nurses involves the ability to suggest the type of help that is in tune with caregivers’ needs as revealed in these asked questions.

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