

Female Caregivers of Stroke Survivors: Coping and Adapting to a Life That Once Was

Karen L. Saban, Nancy S. Hogan

ABSTRACT

Despite the prevalence of women caring for stroke survivors, relatively little research has focused specifically on the experience and needs of informal female caregivers of stroke survivors. Therefore, the purpose of this study was to describe the experience of female caregivers who care for an adult family member who has experienced a stroke within the previous year using a qualitative methodology. A sample of 46 female caregivers of stroke survivors completed a demographic form and responded to open-ended written questions exploring their experiences as caregivers and how they coped with changes in their lives during the first year after the stroke. Four concepts emerged from the data: losing the life that once was, coping with daily burdens, creating a new normal, and interacting with healthcare providers. Findings suggest that female caregivers of stroke survivors grieve the life that they once shared with the stroke survivor and struggle to cope with multiple family and work demands while trying their best to interact with healthcare providers to attain the best possible care for their loved ones. Recognizing the unique challenges of female caregivers of stroke survivors may help nurses provide better support and resources to meet their needs.

Preliminary data from the Centers for Disease Control and Prevention reports that stroke is the fourth leading cause of death in the United States, after heart disease, cancer, and lower respiratory disease (Centers for Disease Control and Prevention, 2011). Approximately 17% of persons experiencing a stroke die within the first year; however, most survive the original traumatic event with varying degrees of emotional, physical, and cognitive disabilities (Lloyd-Jones et al., 2010). It is estimated that about 80% of stroke survivors are discharged home and live for at least 5 years after experiencing a

stroke (National Family Caregiver Association, 2007; Rosamond et al., 2007), resulting in 5.5 million stroke survivors in the United States with, over one million experiencing significant long-term physical disabilities.

Stroke patients may have profound functional limitations, such as mobility problems, cognitive impairments, urinary incontinence, speech and communication difficulties, and personality changes. These impairments may last indefinitely, requiring lifelong caregiver assistance. Even with paid formal assistance (i.e., home health aide), family members are frequently faced with a multitude of stressors ranging from coordination of medical care to 24-hour care of their loved one. Studies have consistently shown that family caregivers are at risk for developing physical and emotional problems (Berg, Palomaki, Lonnqvist, Lehtihalmes, & Kaste, 2005; Green & King, 2007; Schlote, Richter, Frank, & Wallesch, 2006; Ski & O'Connell, 2007; van Exel, Koopmanschap, van den, Brouwer, & van den Bos, 2005). The link between stress and physical health, especially cardiovascular disease, has been well documented in the general population as well as in informal caregivers. For example, in one study, investigators reported an almost 2-fold increased risk of coronary heart disease in caregivers of ill spouses (Lee, Colditz, Berkman, & Kawachi, 2003).

Women clearly bear the burden of informal caregiving in our society with 59%–75% of caregivers being women (Family Caregiving Alliance, 2003). The economic value of informal caregiving that women provide in the United States each year is estimated to be \$148 billion to \$188 billion (Arno, 2002); however,

Questions or comments about this article may be directed to Karen L. Saban, PhD APRN RN CNRN, at ksaban@luc.edu. She is an assistant professor at the Marcella Niehoff School of Nursing, Loyola University Chicago, Chicago, IL, and a research health scientist at the Center for Management of Complex Chronic Care, Edward Hines, Jr., VA Hospital, Hines, IL.

Nancy S. Hogan, PhD RN FAAN, is a distinguished professor and the director for research at the Marcella Niehoff School of Nursing, Loyola University Chicago, Chicago, IL.

The study was supported by the Loyola University Chicago, the Palmer Foundation, and the Chicago Institute of Neurosurgery and Neuroresearch Foundation. In addition, Dr. Saban was supported by a 3-year Veterans Affairs Health Service Research and Development Postdoctoral Fellowship (TPN-42-001).

The views expressed do not necessarily reflect the position or policy of the U.S. Department of Veterans Affairs or the United States Government.

The authors declare no conflicts of interest.

Copyright © 2012 American Association of Neuroscience Nurses

DOI: 10.1097/JNN.0b013e31823ae4f9

these values do not take into account financial losses related to female caregivers reducing their employment commitments or leaving paid work to provide unpaid care (Berg & Woods, 2009). Furthermore, female caregivers spend 50% more time providing care than their male counterparts (Family Caregiving Alliance, 2003) although women comprise 46.9% of the total labor work force in the United States (U.S. Department of Labor, 2010).

Studies focusing on caregivers of individuals with dementia have found that female caregivers experience caregiving significantly different than men. For example, in a study of 283 informal spousal caregivers (198 women and 85 men), women reported significantly higher levels of caregiver burden and had nearly twice the odds of providing support related to toileting assistance than men (Brazil, Thabane, Foster, & Bedard, 2009). Other studies have found that female caregivers experience significantly poorer psychological well-being than men (Franzen-Dahlin, Larson, Murray, Wredling, & Billing, 2007). In a meta-analysis (Pinquart & Sorensen, 2003), investigators found that female caregivers reported higher levels of depression than men.

Despite the prevalence of women caring for stroke survivors, relatively little research has focused specifically on the experience and needs of informal female caregivers of stroke survivors. In a meta-ethnographic review of qualitative literature related to caregivers of stroke survivors between the years of 2006 and 2009, the authors found “the lack of attention to similarities and differences between males and females in their experience of being a stroke carer [as] striking” (Greenwood & Mackenzie, 2010, p. 274), highlighting the need for more research examining the relationship of gender and the caregiving experience.

In a study of 38 female spousal caregivers of stroke survivors (Green & King, 2010), investigators found that, despite an improvement in functional outcomes of the stroke survivor over the first year after the stroke ($F(2) = 4.583, p = .017$), level of depression ($F(6,32) = 3.087, p = .017$), and marital satisfaction ($F(6,32) = 3.961, p = .004$) worsened for the wife caregiver. However, findings of gender differences of stroke survivor informal caregivers have been inconsistent. For example, some researchers did not find any differences between male and female caregivers of stroke survivors in terms of caregiver risk of depression (Grant, Bartolucci, Elliot, & Giger, 2000). In contrast, other studies have suggested that female caregivers of stroke survivors experience greater caregiver burden (Morimoto, Schreiner, & Asano, 2003), physical complaints, and symptoms of depression ($p = .047, d = .37$) and anxiety ($p = .029, d = .41$; Alexander & Wilz, 2010) than male

Because women are often the principal caregivers for many stroke survivors, a better understanding of their experiences and the meaning they ascribe to their experiences would help clinicians better support them.

caregivers. Findings from another study suggested that female caregivers tend to experience distress earlier in the caregiving process than male caregivers (Simon, Kumar, & Kendrick, 2009). Variation in time since stroke, relationship to stroke survivor, as well as instrument selection may account for the discrepancies in findings.

Several literature reviews of caregivers of stroke survivors have been published, demonstrating an extensive quantitative research database. Furthermore, there are several studies focusing on female caregivers in other areas, for example, caregivers of AIDS patients (Kipp & Nkosi, 2008), persons receiving chronic hemodialysis (Wicks, Bolden, Mynatt, Rice, & Acchiardo, 2007), and individuals with multiple sclerosis (Waldron-Perrine, Rapport, Ryan, & Harper, 2009). However, few qualitative research studies were found that specifically addressed the needs of female caregivers who care for stroke survivors and the meaning that these women give to their experiences. A better understanding of female caregivers of stroke survivors' experiences and the meaning they give to their changed lives would assist clinicians in better supporting this vulnerable population. Furthermore, understanding the ways caregivers cope and adapt or fail to adapt to their unanticipated but permanently changed lives would help health providers design stroke after-care models that would benefit female caregivers. Therefore, the purpose of this study was to conduct a qualitative study to describe the experience of female caregivers who care for an adult family member who has experienced a stroke within the previous year.

Method Sample

This study represents the qualitative component of a mixed method study to investigate female stroke caregivers' psychological stressors and physical health and to gain an understanding of the kinds of problems caregivers may have in coping and adapting to the

aftermath of the stroke as well as the types of resources that may be helpful to them. To address the questions of caregivers' perceptions of coping and adapting after a loved one's stroke, a qualitative descriptive design was used. A purposeful sample of caregivers of individuals who had a stroke provided information-rich data about their personal experiences of coping and adapting to providing round-the-clock care to a loved one. A sample of 46 female caregivers of stroke survivors were recruited nationally via recruitment flyers distributed at stroke caregiver support groups, social networking internet sites, and several neurology/neurosurgical outpatient clinics in the Midwest. Women who were interested in participating in the study were asked to contact the study personnel and were enrolled in the study if they met study inclusion criteria. Inclusion criteria for participants were (a) women aged 18 years or older and (b) providing unpaid care to a significant other who experienced a stroke within the past 3–12 months. Participants were also required to be able to speak, read, write, and understand English. The study was approved by the institutional review board, and written consents of participants were obtained. Participants were provided a \$25 gift card for participating in the study.

Procedure

Participants received packets of written study materials in the mail with addressed postage-paid envelopes for returning the completed study data. Items in the packets included a socio-demographic form to document such data as age, educational level, and annual income as well as a written questionnaire containing open-ended questions exploring the experience of female caregivers of stroke survivors and how they coped with changes in their lives during the first year after the stroke. Open-ended questions were as follows: (a) What are some of the problems that you are dealing with as a family caregiver at this time? (b) What types of support would make your life easier? (c) What could the doctors, nurses, and other providers do differently to better assist you? (d) Is there anything else that we did not ask you about that you feel is important for us to know about your experience? Participants were provided ample space to respond to the open-ended questions.

Participants

Age of participants ranged between 18 and 73 years (mean = 56.2 years, $SD = 10.32$ years). Most participants were married ($n = 30$, 65.2%) and White ($n = 38$, 82.6%). In addition, most had at least a college degree ($n = 27$, 58.7%), with 30.4% ($n = 14$) with a postgraduate degree. More than half (52.7%)

of the sample was employed, with 20.8% ($n = 6$) retired. Most participants were living with the stroke survivor ($n = 39$, 84.8%). Relationship with the stroke survivor varied, with 52.2% ($n = 24$) as the wives of the survivor, 39.1% ($n = 18$) as children of the survivor, and only 3.8% ($n = 2$) as either a significant other to the survivor or mother of the survivor. The participants' various ages and relationships to the individuals who had a stroke potentiate the transferability of findings to similar populations.

Analysis

Constant comparative methods were used for analysis of open-ended questions. The set of formal procedures used to analyze data allow researchers to make valid inferences from open-ended written responses to questions in survey research (Krippendorff, 2004). Participants addressed the research questions and then proceeded to write about their pent-up thoughts and feelings related to their lives as caregivers. Data were analyzed as a whole to account for meaning statements provided by the participants. Then, data were analyzed individually, with each of the authors analyzing the presence of conceptually similar data separately with the goal of identifying clusters of words, phrases, or sentences with similar content and assigned a category/concept name. When approximately half of the data had been analyzed, authors compared findings and refined codes and category/concept names. As data analysis proceeded, the authors coded the data together until categories/concepts were saturated and no new data emerged. The authors constantly compared the fit of new data with extant categories/concepts to assure that the participants' words and meaning were faithfully represented and descriptions characterized the meaning of their experiences. Memos were generated throughout the data analysis process to maintain an ongoing account of thoughts and insights and any biases related to the data analysis process.

Concept validity was enhanced through confirmation of the categories and their properties by the authors who continually assessed the conceptual match between the written words provided by caregivers who had lived through the day-to-day coping and adapting of the unexpected stroke of a family member and were living with their changed lives as a family member caregiver. Empirically derived categories, subcategories, and exemplar quotations were derived directly from participant data. Care was taken by authors to not interpret the meaning provided by participants. Findings showed a direct correspondence between the participants' written words, the derived conceptual definitions, categories/concepts, and inferences drawn from the findings. Assessment of

validity requires the researcher to question whether or not the inferences made in the study are accurate and well founded. By faithfully attending to the words and meaning provided by participants, validity was enhanced.

Meaning Context

Content analysis data analysis procedures require that the researcher analyze the phenomenon within the personal–environmental context of the question, “What is the context relative to which the data are analyzed?” (Krippendorff, 2004). The context for this data analysis is female caregivers’ experience of stroke survivor family members and the personal and environmental stressors/problems encountered as they coped and adapted to this life crisis.

Findings

The purpose of this study was to conduct a qualitative study to describe the experience of female caregivers who care for an adult family member who has experienced a stroke within the previous year. The data analysis resulted in four key categories with related subcategories that conceptualize the process of struggling to cope and adapt with irreversible losses. The key categories of meaning are losing the life that once was, coping with daily burdens, creating a new normal, and interacting with healthcare providers. The theme struggling to cope and adapt with irreversible losses represents the latent content of the text. It subsumes the substantive meaning across categories/concepts (see Figure 1 depicting taxonomy of categories).

Losing the Life That Once Was

Caregivers of stroke survivors lose the life that once was the instant that their loved one experienced the

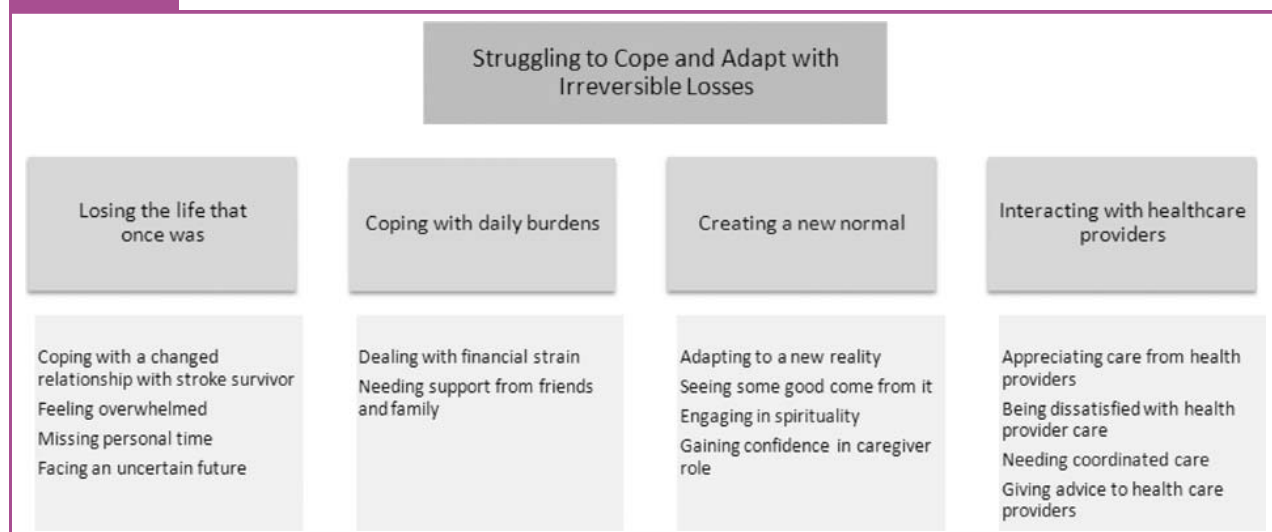
stroke. Caregivers and the stroke survivors’ lives were instantly and forever changed because of the irreversible brain injury sustained by the stroke survivor. Data analysis resulted in four subcategories: (1) coping with a changed relationship with the stroke survivor, (2) feeling overwhelmed, (3) missing personal time, and (4) facing an uncertain future.

Coping With a Changed Relationship With Stroke Survivor

Participants expressed distress related to the changes brought about in their relationship with the stroke survivor because of the stroke. Participants returned to this theme as they attempted to make meaning of their changed lives. Their relationships with the stroke survivor was changed cognitively, emotionally, and physically as caregivers adapted to the significantly altered relationships with loved ones. Many participants grieved the loss of the person they once knew. This change in the relationship was particularly poignant among married couples. One woman wrote, “My husband’s stroke has been devastating for my family. Our lives will never be the same. Our financial, emotional, and physical relationship is ruined. It is very difficult to explain the loss of a life partner due to his stroke. His apraxia and cognitive deficits are very difficult to overcome.” Another wife explained that she missed making day-to-day decisions with her husband, “...not being able to adequately communicate together – to be able to discuss decisions, big and little—as we’ve done the past 43 years.” The significance of how the stroke changed the marriage was an on-going stressor for participants.

Adult children who cared for a parent also identified changes in their relationship because of the stroke. One daughter caregiver wrote, “Mother’s emotional status and ability to cope with and accept the

FIGURE 1 Taxonomy of Categories and Subcategories



mother–daughter role reversal are chief concerns at the present time.” Another participant expressed distress by revealing, “Dad has memory loss as a result of his stroke. The transition from who he was to who he is now is painful, sad, confusing, and frustrating. Often these emotions are present at the same time.” This overriding theme of loss was evident throughout the comments made by participants.

Caregivers also expressed their difficulty coping with the abrupt changes in the stroke survivor’s personality. The stroke survivor was no longer who he or she had been. The caregiver was compelled to acknowledge their changed reality and to deal with the consequence of having to learn to cope and adapt to their new life on a moment-to-moment basis. Caregivers described that, because of the brain injury, their loved one was often “difficult to handle,” “cranky,” “uncooperative,” and “depressed.” One woman described how her husband’s depression resulted in his unwillingness to get out of bed. Caregivers described their loved ones being angry with them for no apparent reason. As a consequence of the negative changes in the stroke survivors’ personalities many caregivers felt unappreciated and overwhelmed. One wife said, “All I do [for] my husband and he doesn’t say thank you unless I prompt him to. That hurts most of the time.” Another wrote, “Feeling much unappreciated. Brain-injured patients aren’t always nice and rarely say thanks.”

Feeling Overwhelmed

Caregivers identified feeling overwhelmed with the physical demands on their time and energy because of their loved ones sustaining a stroke. Constancy of care, physical demands and time constraints were areas frequently described by caregivers. Participants identified being continually needed by the stroke survivor to assist him or her with physical needs, including mobility, toileting, and hygiene. In addition to the physical demands, the caregivers described being on-call 24/7 to accommodate the stroke survivor’s needs. One participant wrote, “He calls me to his room every 10 minutes.” Another wrote: “I am up multiple times at night to aid my stroke victim husband.” The reality of being on-call to the stroke survivor at all times resulted in the caregiver being fatigued because of sleep deprivation. One caregiver expressed, “I get very tired sometimes. There are never enough hours and I don’t have the best physical stamina to get everything done all the time.” Another said, “Lack of sleep. Always interrupted with spouses needs.” Caregivers commonly described how the constant interruptions prevented them from completing necessary tasks such as caring for their home. They also described the stress

of assuming each of the responsibilities that the stroke survivor had completed prior to the stroke. Caregivers expressed their frustration, “I have to do it all.” Many caregivers describe their lives as “overwhelming,” “tiring,” and “disorganized.” One woman wrote, “I feel overwhelmed almost all of the time and alone.” The demands of caregiving were both emotionally and physically exhausting, resulting in caregivers feeling unable to balance the multiple and often conflicting demands of caregiving.

Missing Personal Time

Caregivers also cited loss of personal time as a constant issue that they faced after the stroke. The demands of caregiving while taking on additional responsibilities around the house left little personal time for the caregiver. One participant described the loss of personal time because of the stroke as “[I have] no uninterrupted time for personal things, including showers/baths, TV program or a movie, a chance to read or paint or play the organ. No chance to leave the house for a walk or to bike...” Another described, “I cannot leave when I want to,” and “I have no downtime.” Others talked about how they did not have time to socialize or spend time with friends and family. A daughter wished she could “go out for fun and not worry about Dad.” A wife wrote, “I have to abandon my family and friends to care for my husband.” A mother wrote about neglecting her children, “My children get less time, and this is when I need to give them more time.” Another spouse expressed, “I am missing time with my grandchildren and friends.”

Facing an Uncertain Future

In addition to experiencing significant life changes because of the stroke, caregivers also expressed concerns regarding their uncertain future, as it related to the stroke survivor’s future. One participant worried that “another stroke may be looming.” Another participant stated, “...a big stressor is not knowing what the future holds: “Will he have another stroke? I feel I am coping OK with this one but additional dependence, need for assistance might be too much.” Another wrote, “[There are many] what ifs...such as will she be able to successfully return to work? Will she be able to live independently?” Other participants describe how they were unable to fulfill their dreams because of the stroke. One stated, “I feel that I have put a lot of dreams on hold, such as going away to college and much more.”

In summary, the stroke resulted in life-altering changes for the informal caregiver. Everything from their relationship with the stroke survivor to their plans for the future was swiftly and unexpectedly

turned upside down. Caregivers lived with daily fears of their unknown future.

Coping With Daily Burdens

Caregivers identified several areas that they had to cope with during the year after the stroke. In particular, dealing with financial strain and needing support from friends and family were areas of particular concern.

Dealing With Financial Strain

Many participants described their concerns regarding the impact of the stroke on their finances. Some participants described the loss of the stroke survivor's income as well as their own need to retire. This loss of income resulted in their having to live from "paycheck to paycheck." Some feared that they would "run out of money." Mounting medical bills and lack of adequate medical insurance added to their plights. A wife wrote that she would be "in total poverty should husband die." Another wrote, "So we have cashed out most of our house to be able to pay for his medical bills. This is one of the biggest stressors...we now have essentially no retirement fund." Another caregiver said, "I skipped healthcare for myself for money reasons." Furthermore, future financial stability was also a significant concern. Some participants shared that they essentially lost their retirement savings because of the stroke. Better assistance with "navigating the insurance maze" and help with financial planning were suggested as important needs of caregivers.

Needing Support From Friends and Family

Caregivers often expressed feeling abandoned by family members and friends. One woman wrote, "My friends have kept their distance. This is very disappointing." Some caregivers tried to engage family members to help but found little cooperation. One woman wrote, "I wish all the people that said that they would help us would come by and see if we needed anything. I feel like the neighborhood beggar. I actually have asked for help and been rebuffed." Caregivers felt regret and frustration that their children did not offer on-going help to lighten the burden of doing everything alone. They expressed feeling discouraged by the apparent lack of concern shown by children and other family members for the daily plight of the caregiver. One caregiver expressed, "I am sole caregiver. There is lack of concern, communication, sharing, and responsibility among family members." Another said, "I wish my daughter would come and stay with her dad once in awhile to help out."

Lack of emotional support from family and friends was compounded by lack of available respite for the

caregiver. Lack of respite was a key stressor that most of the caregivers identified. Caregivers expressed the need for assistance with providing direct care for their loved one as well as help with grocery shopping, housecleaning, and other errands. Many participants simply wanted to be able to get out of the house sometimes: "If I could just go to the grocery store once in a while without always hurrying." Caregivers wanted reliable, trustworthy assistance. Some caregivers had paid assistants, whereas others depended on friends and family to help. Those who relied on unpaid assistance sometimes felt uncomfortable asking for help. One caregiver explained, "Family members are great, but most of the time we have to call and ask for help. I wish they would come on their own and do some things. They know what I can't do but I still have to ask or do them myself."

On the positive side, some participants discussed the value of the support they received from friends and families in providing them with the strength to continue their difficult jobs as caregivers. One woman who was caring for her mother expressed, "I was lucky enough to have a wonderful, understanding husband who took time off of work when times were especially stressful." Another caregiver said, "I have a wealth of good and loving family and friends who support me without being intrusive." Many caregivers stressed the importance of making time to see friends and to socialize. However, although friendly gestures were greatly appreciated, they also needed "true friends" who they could openly talk to about their deepest fears.

Creating a New Normal

Caregivers identified striving to create a new normal. This process encompassed several subprocesses, including adapting to a new reality, seeing some good come from it, engaging in spirituality, and gaining confidence in caregiver role.

Adapting to a New Reality

Adapting to a new reality included recognizing the difficulty of caregiving and accepting the permanence of their changed lives. One woman wrote, "Caregiving is not for the faint of heart." Caregivers also discussed the fact that their lives were now centered in giving care and comfort to their loved ones. One caregiver commented that it was helpful to have their physician tell her that "This is a marathon, not a sprint." Although caregivers stressed the importance of doing their best to care for their loved ones, some participants recognized that they needed to take care of themselves and "replenish reserves" to have the strength necessary

to be effective caregivers. Some participants described grieving for their losses, accepting their new lives, and moving on. One woman wrote, "After all the lovely cards and the hot meals are delivered, there has to be personal, private ways that an individual deals with, grieves, and accepts what has happened." Another woman simply accepted her changed reality as a matter of fact. "The positive aspect of caregiving was difficult, because it neither is positive or negative. It is what it is."

Seeing Some Good Come From It

Some caregivers pointed out that, although caregiving was very difficult, they were able to find some good in their experiences. One woman wrote, "There is a joy in caring for someone you love. It doesn't mean everything goes smoothly." Others wrote about how they gained strength from the courage their loved ones showed in dealing with the stroke and its after-effects. A wife expressed, "My husband is doing everything he possibly can do to get better." Some caregivers wrote about how the stroke strengthened their relationships with the stroke survivors. A daughter commented, "I never had a close relationship with my Dad, but after the stroke I have a relationship with him. I have forgiven him for things in the past." One wife wrote, "There is a wonderful side of caregiving for my husband—it has deepened our relationship and forced us to sort out what is truly important in our lives. I wouldn't trade places with anyone for this reason."

Engaging in Spirituality

Some caregivers found strength in relying on their spiritual beliefs to help them cope with their losses. One caregiver expressed, "...only God know what the future holds, so I'll just keep trusting him." Another said, "I would not be able to do this without a strong spiritual life." Other caregivers found comfort in praying, meditating, journaling, writing poetry, caring for animals, gardening, and painting. One woman wrote, "I have written poetry and have a WOW (word of the week) that I hang on to. Examples have been 'Equilibrium' (when I was just trying to maintain it). 'Nike' (just do it!) when I was facing a mountain of issues and decisions, 'Hoops' (as in jumping through, and hoop circle-of-love)...[and] 'Prevail' when I needed to get through each day or perhaps the next few minutes."

Gaining Confidence in Caregiver Role

Caregivers discussed how learning about the stroke survivors' illness and needed care helped them to better deal with being caregivers. The internet was a frequent source of knowledge. One woman wrote,

"It was just scary never having experienced a stroke first hand. I learned a lot from the Internet and asking questions and taking notes to refer back to." Many caregivers expressed the initial fear that they had about caring for the stroke survivor and how they gained confidence with time. One said, "I am doing much better than in the beginning."

Interacting With Healthcare Providers

During the turmoil of the first year after the stroke, caregivers often sought out healthcare providers for advice and guidance for dealing with the challenges of caring for their loved one. Some caregivers related positive experiences when interacting with healthcare providers. They expressed appreciating the care received from healthcare providers, whereas other participants identified being dissatisfied with healthcare provider care. Many participants identified the need for more coordinated care and offered advice to healthcare providers caring for stroke survivors and their caregivers.

Appreciating Care From Healthcare Providers

Caregivers identified several ways in which healthcare providers assisted the informal caregiving in providing quality care. Recognizing the caregiver's need for support and referring the caregiver to a support group was acknowledged by several participants. An example of a caregiver recognizing the need for support was expressed as, "I think the value of having a support group or individuals who you can call just who listen and understand is huge." Another participant stressed the importance of "having people who have been through this to talk to, who really understand...what other people find useful." Participants also expressed a need for support groups that met the needs of younger caregivers: "Very little support exists for the unique challenges faced by the significantly younger spousal caregivers—support groups are directed either towards care giving children or same stage-of-life spouses."

Being Dissatisfied With Health Provider Care

Although many caregivers expressed their appreciation of healthcare providers, a few were frustrated with the care they and their loved ones received. One participant wrote, "Care, care, care, instead it seems to be all about money to them or they do as little as possible (with a few great exceptions)." Another said, "[I] do not trust hospitals or 'professional' caregivers...." Others expressed their dissatisfaction with not being listened to, stating, "...many of [the providers] simply do not listen." One woman wrote, "Listen and believe me when I tell them about symptoms and reactions to drugs."

Caregivers wanted healthcare providers to provide information on the expected recovery trajectory of the stroke patient that was both realistic yet hopeful. For example, one participant said, “I do know strokes are all different so there are no really ‘normal’ patterns of healing, but I also felt like the doctors did not tell me what to expect.” Another said, “Have more optimism about the stroke survivor’s recovery.” Caregivers also wanted on-going information on what to expect at different phases of the stroke survivor’s recovery process. For example, one participant said, “Give better direction and advice as to what to expect and what the best recommendation would have been when mom came home. They should [have] recommended an assessment—before we went ahead with bathroom remodel.”

Needing Coordinated Care

Coordination of care was another common thread in responses related to interacting with healthcare providers. Participants expressed a desire for healthcare providers to help them organize and coordinate the frequently complex care needs. One participant stated, “Help me assemble my husband’s personal health record to enhance coordination of care.” Another expressed, “It would help if [the providers] were all on the same page—sometimes I feel like I have to be the doctor to sort out all of the differing opinions of specialists.” Another participant summarized the need for coordinated care by saying, “I wish I could have a doctor/nurse that could ‘manage’ ‘advise,’ ‘interpret,’ and help with feedback from all specialists.” In addition, caregivers desired better coordination of clinic appointments with one stating, “Minimize multiple appointments and combine them when I visit.”

Giving Advice to Healthcare Providers

Participants had several suggestions for healthcare providers to improve care. Advice to healthcare providers centered on the healthcare provider referring the caregiver to appropriate resources, managing medications, and acting in a caring manner. Caregivers expressed the need for healthcare providers to help them identify appropriate resources for both the patient and themselves. For example, one caregiver wanted to be referred to a primary care physician “that is experienced with stroke patients.” Others wanted help with locating support groups, mental health professionals, transportation to appointments, respite care, and obtaining assistive devices such as ramps.

Managing medications was identified by many caregivers as an important need from healthcare providers. Caregivers wanted more information about

the coordination of medications, potential interactions, and side effects. In addition, they wanted to feel confident that the healthcare provider was prescribing appropriately and monitoring the medications. For example, one participant said, “[don’t] jump to add more medication with every symptom just because he had a stroke.” Another advised, “Keep closer watch on husband’s medication.” Caregivers expressed a need for healthcare providers to provide them with accurate and detailed information about medication management. An example was “They could have explained the medications better. I was given a list but not enough detail (don’t administer if sugar is below 100, for example).” In addition, caregivers preferred relevant information needs to be provided throughout the recovery period. The consequence was the caregiver feeling uncertain and inadequate regarding issues related to the caregivers role in medicating their loved one.

Finally, caregivers wanted to feel like the healthcare provider cared about them and their loved ones. They wanted the healthcare provider to spend time with them and “not be in a hurry to see the next patient.” However, some caregivers expressed unrealistic expectations of the provider. For example, one said, “Fix the stroke so she has a life that’s normal.”

Discussion

This study highlights the unique experiences of women caring for stroke survivors. Findings showed that female caregivers were preoccupied with four kinds of stressors characterized by facing permanent and irreversible losses while trying to cope with daily burdens and struggling to create a new normal. Healthcare providers positively and negatively affected the ability of the caregivers to cope and adapt to their changed lives. The key concepts that reflect this process are as follows: (a) losing the life that once was, (b) coping with daily burdens, (c) creating a new normal, and (d) interacting with healthcare providers are discussed.

Losing the Life That Once Was

The key concept of losing the life that once was characterized by the caregiver having to cope with a changed relationship with the stroke survivor, feeling overwhelmed, missing personal time, and facing an uncertain future. The concept that caused the most distress was coping with the changed relationship with the stroke survivor. These concepts were particularly evident in spouses’ comments. In some instances, the stroke survivor’s personality was so drastically changed because of the stroke that the stroke survivor no longer seemed like the same

person that the caregiver had known prior to the stroke. Grief is a common response to a significant loss (Noyes et al., 2010). Although the literature related to grief in caregivers is scant, there is growing evidence that caregivers, especially those who care for their loved ones with cognitive deficits such as found in persons with dementia or brain injury, experience significant grief (Chiambretto, Moroni, Guarnerio, Bertolotti, & Prigerson, 2010; Meuser & Marwit, 2001; Noyes et al., 2010; Ott, Sanders, & Kelber, 2007). Boss (1999) coined the term “ambiguous loss” to describe the grief experienced by caregivers. Ambiguous loss can occur when the person one is grieving for is physically still present but cognitively no longer the same person (Sanders & Adams, 2005). Ambiguous loss is considered one of the most difficult types of grief to cope with because of the uncertainty associated with it and the lack of societal rituals often associated with the death of a loved one (Boss, 1999).

Studies have found that grief is a significant predictor of depressive symptoms in caregivers of individuals with Alzheimer disease and dementia (Marwit & Meuser, 2002; Sanders & Adams, 2005). Furthermore, it has been suggested that caregivers of people with Alzheimer experiencing grief may inaccurately receive a diagnosis of depression and not be appropriately treated (Sanders & Adams, 2005). Surprisingly, no published research was found examining grief in informal caregivers of stroke survivors, although several studies identified loss as an important experience of caregivers of stroke survivors (Coombs, 2007; Green & King, 2009; Greenwood & Mackenzie, 2010). Our results suggest that, because of the multiple losses, grief may play a predominant role in the lives of female caregivers.

Compounding the caregivers’ grief over the loss of the person that they once knew, caregivers reported losses in other important areas of their lives, such as feeling overwhelmed with competing family demands, missing personal time, and facing an uncertain future. Our findings are in agreement with those of Coombs (2007), in which eight spouses (five women and three men) of stroke survivors were interviewed at least 1 year after the stroke regarding their experiences of providing care to a stroke survivor. Coombs identified the experience of profound loss as an important theme, which included loss of leisure time, loss of freedom, and loss of marital partner. Our findings extend those of Coombs in that findings from this study identified that caregivers lived with the stress of an uncertain future and the loss of the anticipated future that was now not possible. In addition, our sample consisted of a younger group of participants (mean age, 56.2 years) compared

with sample in Coomb’s study (65.5 years of age). Younger caregivers may be more concerned with the uncertainty of the future than older caregivers.

Coping With Daily Burdens

In addition to feeling significant loss related to the changed relationship after the stroke, female caregivers of stroke survivors also found it necessary to cope with a multitude of daily burdens. High levels of caregiver stress and burden of stroke survivors has been well documented in the literature (Haley, Roth, Howard, & Safford, 2010; King, Ainsworth, Ronen, & Hartke, 2010; Rigby, Gubitz, & Phillips, 2009; Saban, Sherwood, DeVon, & Hynes, 2010). Our findings indicate that female caregivers are most concerned with dealing with financial strain, needing support from friends and family, and needing respite. These issues are similar to those reported by King et al., (2010) in a mixed methods study of 58 caregivers (45 women and 13 men), which examined the types and frequency of caregiver issue during acute rehabilitation and first 3–4 months postdischarge; however, the additional need for respite was identified in our study. The longer duration since the stroke (our study included caregivers 3–12 months after stroke, whereas King et al. interviewed caregivers within 3–4 months after stroke) may have accounted for the caregivers, in this study, identifying the need for respite.

Our findings are also consistent with those of several other studies in that participants identified needing support from others as important in helping them cope with their changed lives (Buschenfeld, Morris, & Lockwood, 2009; Coombs, 2007; Greenwood & Mackenzie, 2010; Steiner et al., 2008). Steiner et al., (2008) stressed that social support includes both emotional and physical support, which is in agreement with our findings that caregivers expressed the need for both emotional support and physical help with caring for their loved one. However, in contrast to the study by Coombs (2007), our participants expressed the despair of often feeling abandoned by their friends and family who were viewed as seldom reaching out or spontaneously offering to help the caregiver. This sense of feeling abandoned by family members resulted in caregivers feeling alone to deal with their despair. Assisting caregivers in finding strategies to request and obtain help from family members may be an important role of nurses and other healthcare providers.

Creating a New Normal

The participants identified the first year after the stroke as a time of making significant adjustments in coping and adapting to their permanently changed

lives. Some of the participants accepted their changed life and began creating a new normal that included engaging in spirituality, gaining confidence, and seeing some good coming from caring for a loved one. Realizing that caregiving is constant and difficult was a finding identified in our study that was not found in the literature.

Seeing some good or benefit-finding was another adapting mechanism identified by some caregivers. Benefit-finding has been examined in other studies of caregivers in relation to the well-being of the caregiver (Kim, Schulz, & Carver, 2007; Pakenham & Cox, 2008, 2009). Benefit-finding is a term used to describe the “phenomenon of personal growth or positive changes after an encounter with a challenging or traumatic life experience” (Kim et al., 2007, p. 283). Although no studies were found that specifically examined benefit-finding in caregivers of stroke survivors, some studies did consider optimism and hope in stroke survivor caregivers (Coombs, 2007; Silva-Smith, 2007). Although these concepts are different than benefit-finding, they are related. For example, Coombs (2007) found that caregivers, despite their struggles, were sustained by their hope in the future. Kim et al., (2007) have suggested that benefit-finding may help caregivers adapt to their changed lives. Further examination of the role of benefit-finding in caregivers of stroke survivors is needed. Finally, personal growth as a measurable outcome of grieving the loss of a loved one requires further exploration in the caregiver population (Gamino, Hogan, & Sewell, 2002; Hogan, Greenfield, & Schmidt, 2001; Hogan & Schmidt, 2002). Further research will clarify the degree to which stroke caregiver grief is similar and/or different with regard to personal growth/benefit finding and is a fertile area for further study.

Study participants described spirituality as an important factor in creating a new normal. Participants in our study expressed spirituality by a wide range of practices, including praying, writing poetry, caring for animals, and gardening. Pierce et al. (2008), in a qualitative study of 36 caregivers of stroke survivors (69.4% women), identified four key components: feeling the presence of a greater power, practicing rituals, being one with nature, and interacting with family. Findings from our study supported each of the concepts identified in Pierce et al. (2008), except some participants in our study identified interactions with family as a stressor.

Gaining confidence in the caregiver role was associated with caregivers creating a new normal. Surprisingly, few published qualitative studies identified the notion of gaining confidence in caregivers of stroke survivors. Backstrom and Sundin (2009), in

a qualitative study of nine caregivers (both men and women) of stroke survivors 1 year after discharge from a rehabilitation clinic, identified a related concept of “being familiar with new routines” (p. 1478). Silva-Smith (2007), in a study of 12 new caregivers caring for stroke survivors 4 weeks after discharge from rehabilitation, also refers to caregivers developing routines. Although the concept of developing a routine is similar to gaining confidence, it is different in that gaining confidence is a higher-level concept associated with self-esteem and a changed sense of self.

Interacting With Healthcare Providers

Responses described caregivers’ perception of interacting with healthcare providers as centered on appreciating care from healthcare providers, being dissatisfied with healthcare provider care, needing coordinated care, and offering advice to healthcare providers. Only a few studies were found that specifically addressed the relationship between the stroke caregiver and healthcare provider and mainly focused on areas of improvement needed from the providers. Areas cited for improvement identified in these studies were consistent with those in our study and included healthcare providers providing more information regarding resources for caregivers, respite care, nutrition, transportation, and ongoing education (King & Semik, 2006; Moore, Maiocco, Schmidt, Guo, & Estes, 2002). Providing information about respite care was a key need identified in several studies as well as in this study. A unique finding in this study was the need for healthcare providers to assist the caregiver in coordination of care. Coordination of care included management of appointments, treatments, and medications. Female caregivers, who were often juggling the multiple demands of caring for children and working, described the lack of coordination as a significant on-going stressor. Participants in our study also stressed the importance of healthcare providers acting in a caring manner. Several caregivers noticed healthcare providers seemed in a hurry or distracted. In addition, they sensed that healthcare providers failed to listen to or act upon caregivers’ concerns.

Limitations of this study are acknowledged. The data were collected using self-report written responses. The degree to which findings would have been different if one-to-one interviews were done is unknown. The sample consisted of primarily White, well-educated participants. It is suggested that future research include a more heterogeneous sample with regard to income and educational level. Furthermore, we recommend that oral interview methods be used to further query participants on the meaning of

being a caregiver. Finally, our study focused on coping and adapting behaviors of female caregivers during the first year of caregiving. Future research may benefit from exploring how the experience of caregiving changes over time for women caring for stroke survivors.

Implications for Practice

Findings provide evidence that caregivers have specific needs that could be better met by healthcare professionals. Understanding of the unique experiences of female caregivers of stroke survivors is important for nurses to effectively manage care and to provide needed support and guidance to women caring for stroke survivors. Caregivers' lives changed abruptly and irreversibly as their loved ones sustained the stroke, resulting in grieving the permanent changes in their loved ones and their shared relationship. Their grieving added an additional stressor to their need to cope with numerous physical, emotional, social, and cognitive stressors. Recognizing that grief may play a role in the psychological well-being of caregivers is important for nurses in determining the support needs of caregivers. In addition, it may be important for nurses to assist caregivers in developing strategies for requesting and obtaining support from others.

Participants offered several suggestions to healthcare providers to improve care. First, participants advised providers to listen to caregivers' reports of medication problems and changes in the survivors' behaviors and to offer anticipatory guidance to help caregivers regarding what the caregiver can expect during the recovery period. Referring caregivers to a support group was also frequently suggested by participants. In addition, many caregivers found coordination of the stroke survivor's care a significant challenge. Combining multiple appointments into fewer visits was suggested by several caregivers. Finally, respite was a priority for many caregivers in our study. Participants suggested that clinicians assist caregivers in identifying their respite needs and refer them to appropriate resources.

Conclusions

This is one of the first studies to focus on the unique needs of women caring for stroke survivors. In summary, the process of becoming a caregiver began abruptly when their loved one sustained a stroke resulting in varying degrees of cognitive, emotional, and physical disabilities. Upon getting the news of the stroke, the caregiver's shared life that had existed with the loved one before the stroke ceased to exist, and female caregivers were compelled to cope

and adapt to permanent changes in their day-to-day lives. Yet, with time, most of the caregivers began the process of creating a new normal that had meaning and purpose. Finally, participants identified specific actions and attitudes that healthcare providers could adopt, which could increase the effectiveness of providing care to stroke survivors.

Acknowledgments

The authors thank the female family caregivers who so generously provided their time and thought-provoking insights.

References

- Alexander, T., & Wilz, G. (2010). Family caregivers: Gender differences in adjustment to stroke survivors' mental changes. *Rehabilitation Psychology, 55*(2), 159–169. doi:10.1037/a0019253
- Arno, P. S. (2002). The economic value of informal caregiving, U.S., 2000: Conference Proceeding. Paper presented at the American Association for Geriatric Psychiatry, Florida, February 24, 2002. doi:10.1377/hlthaff.18.2.182
- Backstrom, B., & Sundin, K. (2009). The experience of being a middle-aged close relative of a person who has suffered a stroke, 1 year after discharge from a rehabilitation clinic: A qualitative study. *International Journal of Nursing Studies, 46*(11), 1475–1484. doi:10.1016/j.ijnurstu.2009.04.009
- Berg, A., Palomaki, H., Lonnqvist, J., Lehtihalmes, M., & Kaste, M. (2005). Depression among caregivers of stroke survivors. *Stroke, 36*(3), 639–643. doi:10.1161/01.STR.0000155690.04697.c0
- Berg, J. A., & Woods, N. F. (2009). Global women's health: a spotlight on caregiving. *Nursing Clinics of North America, 44*(3), 375–384. doi:10.1016/j.cnur.2009.06.003
- Boss, P. (1999). Insights: ambiguous loss: Living with frozen grief. *Harvard Mental Health Letter, 16*(5), 4–6.
- Brazil, K., Thabane, L., Foster, G., & Bedard, M. (2009). Gender differences among Canadian spousal caregivers at the end of life. *Health & Social Care in the Community, 17*(2), 159–166. doi:10.1111/j.1365-2524.2008.00813.x
- Buschenfeld, K., Morris, R., & Lockwood, S. (2009). The experience of partners of young stroke survivors. *Disability & Rehabilitation, 31*(20), 1643–1651. doi:10.1080/09638280902736338
- Centers for Disease Control and Prevention. (2011). National Center for Health Statistics. Retrieved from <http://www.cdc.gov/nchs/>
- Chiambretto, P., Moroni, L., Guarnerio, C., Bertolotti, G., & Prigerson, H. G. (2010). Prolonged grief and depression in caregivers of patients in vegetative state. *Brain Injury, 24*(4), 581–588. doi:10.3109/02699051003610490
- Coombs, U. E. (2007). Spousal caregiving for stroke survivors. *Journal of Neuroscience Nursing, 39*(2), 112–119. doi:10.1097/01376517-200704000-00008
- Family Caregiving Alliance. (2003). Women and caregiving: Facts and figures. Retrieved from http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=892
- Franzen-Dahlin, A., Larson, J., Murray, V., Wredling, R., & Billing, E. (2007). Predictors of psychological health in

- spouses of persons affected by stroke. *Journal of Clinical Nursing*, 16(5), 885–891. doi:10.1111/j.1365-2702.2006.01744.x
- Gamino, L. A., Hogan, N. S., & Sewell, K. W. (2002). Feeling the absence: a content analysis from the Scott and White grief study. *Death Studies*, 26(10), 793–813. doi:10.1080/07481180290106580
- Grant, J. S., Bartolucci, A. A., Elliot, T. R., & Giger, J. N. (2000). Sociodemographic, physical, and psychosocial characteristics of depressed and non-depressed family caregivers of stroke survivors. *Brain Injury*, 14(12), 1089–1100. doi:10.1080/02699050050203586
- Green, T. L., & King, K. M. (2007). The trajectory of minor stroke recovery for men and their female spousal caregivers: literature review. [Review] [50 refs]. *Journal of Advanced Nursing*, 58(6), 517–531.
- Green, T. L., & King, K. M. (2009). Experiences of male patients and wife-caregivers in the first year post-discharge following minor stroke: A descriptive qualitative study. *International Journal of Nursing Studies*, 46(9), 1194–1200. doi:10.1016/j.ijnurstu.2009.02
- Green, T. L., & King, K. M. (2010). Functional and psychosocial outcomes 1 year after mild stroke. *Journal of Stroke and Cerebrovascular Diseases*, 19(1), 10–16. doi:10.1016/j.jstrokecerebrovasdis.2009.02.005
- Greenwood, N., & Mackenzie, A. (2010). Informal caring for stroke survivors: meta-ethnographic review of qualitative literature. *Maturitas*, 66(3), 268–276. doi:10.1016/j.maturitas.2010.03.017
- Haley, W. E., Roth, D. L., Howard, G., & Safford, M. M. (2010). Caregiving strain and estimated risk for stroke and coronary heart disease among spouse caregivers: differential effects by race and sex. *Stroke*, 41(2), 331–336. doi:10.1161/STROKEAHA.109.568279
- Hogan, N. S., Greenfield, D. B., & Schmidt, L. A. (2001). Development and validation of the Hogan Grief Reaction Checklist. *Death Studies*, 25(1), 1–32.
- Hogan, N. S., & Schmidt, L. A. (2002). Testing the grief to personal growth model using structural equation modeling. *Death Studies*, 26(8), 615–634.
- Kim, Y., Schulz, R., & Carver, C. S. (2007). Benefit-finding in the cancer caregiving experience. *Psychosomatic Medicine*, 69(3), 283–291. doi:10.1097/PSY.0b013e3180417cf4
- King, R. B., Ainsworth, C. R., Ronen, M., & Hartke, R. J. (2010). Stroke caregivers: Pressing problems reported during the first months of caregiving. *Journal of Neuroscience Nursing*, 42(6), 302–311. doi:10.1097/JNN.0b013e3181f8a575
- King, R. B., & Semik, P. E. (2006). Stroke caregiving: Difficult times, resource use, and needs during the first 2 years. *Journal of Gerontological Nursing*, 32(4), 37–44.
- Kipp, W., & Nkosi, T. M. (2008). Factors associated with the self-reported health status of female caregivers of AIDS patients. *Western Journal of Nursing Research*, 30(1), 20–33. doi:10.1177/0193945907302979
- Krippendorff, K. H. (2004). *Content analysis: An introduction to its methodology* (2nd ed.). Thousand Oaks, CA: Sage.
- Lee, S., Colditz, G. A., Berkman, L. F., & Kawachi, I. (2003). Caregiving and risk of coronary heart disease in U.S. women: a prospective study. *American Journal of Preventive Medicine*, 24(2), 113–119. doi:10.1016/S0749-3797(02)00582-2
- Lloyd-Jones, D., Adams, R. J., Brown, T. M., Carnethon, M., Dai, S., De, S. G., ... American Heart Association Statistics Committee and Stroke Statistics Subcommittee. (2010). Heart disease and stroke statistics—2010 update: A report from the American Heart Association. *Circulation*, 121(7), e46–e215.
- Marwit, S. J., & Meuser, T. M. (2002). Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimer's disease. *Gerontologist*, 42(6), 751–765. doi:10.1093/geront/42.6.751
- Meuser, T. M., & Marwit, S. J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *Gerontologist*, 41(5), 658–670. doi:10.1093/geront/41.5.658
- Moore, L. W., Maiocco, G., Schmidt, S. M., Guo, L., & Estes, J. (2002). Perspectives of caregivers of stroke survivors: implications for nursing. *MEDSURG Nursing*, 11(6), 289–295.
- Morimoto, T., Schreiner, A. S., & Asano, H. (2003). Caregiver burden and health-related quality of life among Japanese stroke caregivers. *Age and Ageing*, 32(2), 218–223. doi:10.1093/ageing/32.2.218
- National Family Caregiver Association. (2007). Caregiving statistics. internet. Retrieved from http://www.thefamilycaregiver.org/who_are_family_caregivers/care_giving_statistics.cfm
- Noyes, B. B., Hill, R. D., Hicken, B. L., Luptak, M., Rupper, R., Dailey, N. K., ... Baird, B. D. (2010). The role of grief in dementia caregiving. *American Journal of Alzheimer's Disease and Other Dementias*, 25(1), 9–17. doi:10.1177/1533317509333902
- Ott, C. H., Sanders, S., & Kelber, S. T. (2007). Grief and personal growth experience of spouses and adult-child caregivers of individuals with Alzheimer's disease and related dementias. *Gerontologist*, 47(6), 798–809. doi:10.1093/geront/47.6.798
- Pakenham, K. I., & Cox, S. (2008). Development of the benefit finding in multiple sclerosis (MS) caregiving scale: A longitudinal study of relations between benefit finding and adjustment. *British Journal of Health Psychology*, 13(Pt:4), 4–602. doi:10.1348/135910707X250848
- Pakenham, K. I., & Cox, S. (2009). The dimensional structure of benefit finding in multiple sclerosis and relations with positive and negative adjustment: A longitudinal study. *Psychology and Health*, 24(4), 373–393. doi:10.1080/08870440701832592
- Pierce, L. L., Steiner, V., Havens, H., & Tormoehlen, K. (2008). Spirituality expressed by caregivers of stroke survivors. *Western Journal of Nursing Research*, 30(5), 606–619. doi:10.1177/0193945907310560
- Pinquart, M., & Sorensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging*, 18(2), 250–267. doi:10.1037/0882-7974.18.2.250
- Rigby, H., Gubit, G., & Phillips, S. (2009). A systematic review of caregiver burden following stroke. *International Journal of Stroke*, 4(4), 285–292. doi:10.1111/j.1747-4949.2009.00289.x
- Rosamond, W., Flegal, K., Friday, G., Furie, K., Go, A., Greenlund, K., ... Hong, Y. (2007). Heart disease and stroke statistics—2007 update: A report from the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. *Circulation*, 115(5), e69–e171. doi:10.1161/CIRCULATIONAHA.106.179918
- Saban, K. L., Sherwood, P. R., DeVon, H. A., & Hynes, D. M. (2010). Measures of psychological stress and physical health in family caregivers of stroke survivors: A literature review. *Journal of Neuroscience Nursing*, 42(3), 128–138. doi:10.1097/JNN.0b013e3181d4a3ee
- Sanders, S., & Adams, K. B. (2005). Grief reactions and depression in caregivers of individuals with Alzheimer's disease: results from a pilot study in an urban setting. *Health and Social Work*, 30(4), 287–295.
- Schlote, A., Richter, M., Frank, B., & Wallesch, C. W. (2006). A longitudinal study of health-related quality of life of first stroke survivors' close relatives. *Cerebrovascular Diseases*, 22(2–3), 137–142.
- Silva-Smith, A. L. (2007). Restructuring life: preparing for and beginning a new caregiving role. *Journal of Family Nursing*, 13(1), 99–116. doi:10.1177/1074840706297425

- Simon, C., Kumar, S., & Kendrick, T. (2009). Cohort study of informal carers of first-time stroke survivors: profile of health and social changes in the first year of caregiving. *Social Science and Medicine*, 69(3), 404–410. doi:10.1016/j.socscimed.2009.04.007
- Ski, C., & O'Connell, B. (2007). Stroke: the increasing complexity of carer needs. *Journal of Neuroscience Nursing*, 39(3), 172–179.
- Steiner, V., Pierce, L., Drahuschak, S., Nofziger, E., Buchman, D., & Szirony, T. (2008). Emotional support, physical help, and health of caregivers of stroke survivors. *Journal of Neuroscience Nursing*, 40(1), 48–54. doi:10.1097/01376517-200802000-00008
- U.S. Department of Labor. (2010). Quick stats on women workers, 2009. Retrieved from <http://www.dol.gov/wb/stats/main.htm>
- van Exel, N. J., Koopmanschap, M. A., van den, B. B., Brouwer, W. B., & van den Bos, G. A. (2005). Burden of informal caregiving for stroke patients. Identification of caregivers at risk of adverse health effects. *Cerebrovascular Diseases*, 19(1), 11–17.
- Waldron-Perrine, B., Rapport, L. J., Ryan, K. A., & Harper, K. T. (2009). Predictors of life satisfaction among caregivers of individuals with multiple sclerosis. *Clinical Neuropsychologist*, 23(3), 462–478.
- Wicks, M. N., Bolden, L., Mynatt, S., Rice, M. C., & Acchiardo, S. R. (2007). Insight potentially prevents and treats depressive and anxiety symptoms in Black women caring for chronic hemodialysis recipients. *Nephrology Nursing Journal: Journal of the American Nephrology Nurses' Association*, 34(6), 623–629.

WANTED!

The *Journal of Neuroscience Nursing (JNN)* is seeking authors interested in submitting manuscripts for publication. Although *JNN* is a clinically focused journal, we do include topics addressing nursing practice as a whole; research articles are encouraged as well. Both new and experienced authors are welcome; a new author mentor program is available.

Need topic ideas? A wide variety of articles are possible. *JNN* is actively seeking manuscripts in the following areas:

- Case studies elaborating approaches to care for a challenging or unique patient
- Outcomes studies
- Geriatric aspects of neuroscience nursing
- Pediatric-focused articles
- Novel drug therapies for neurologic diseases
- Intraoperative considerations and surgical instrumentation
- Focused assessment articles (e.g., spine assessment)
- New products related to neuroscience nursing care
- Literature review of a neuroscience-related topic
- Home care of the chronic neurologically impaired patient
- Nursing management in the neuroscience outpatient settings (e.g., nurse-managed back-pain clinic)
- Ethical issues in neuroscience nursing
- Care of the patient undergoing neurointerventional procedures
- Noninvasive surgical and treatment techniques
- Collaborative approaches to care

Guidelines for authors can be found at www.editorialmanager.com/neuronurse/.

To query the editor about a specific manuscript idea, send an e-mail to susan.carroll25@gmail.com. Review time after submission is about 6–8 weeks.