Published in final edited form as:

J Neurosci Nurs. 2010 December ; 42(6): 302–311.

Stroke Caregivers: Pressing Problems Reported during the First Months of Caregiving

Rosemarie B. King, Ph.D, RN,

Research Professor, Northwestern University Feinberg School of Medicine Rehabilitation Institute of Chicago, Suite 1406 345 E. Superior St. Chicago, IL, 60611 rbking@northwestern.edu

Courtenay Rourke Ainsworth, M.S.,

Illinois Institute of Technology 4726 N. Winchester Unit B Chicago, IL 60640 ainscou@iit.edu

Maya Ronen, M.S., and

Illinois Institute of Technology 3105 South Dearborn, Suite 252, Chicago, IL 60616-3793
mayaronen@gmail.com

Robert J. Hartke, Ph.D., MPH

Rehabilitation Institute of Chicago Assistant Professor, Depts. Of PM&R, Psychiatry & Behavioral Science 345 E. Superior St. Room 358B Chicago, Illinois 60611 rhartke@ric.org

Abstract

The major purpose of this study was a) to identify the types and frequency of caregiving problems and associated stress and coping effectiveness. Secondary purposes were a) to examine changes in problem frequency, stress, and coping effectiveness, over time; and b) to identify relationships between problem stress and personal, illness, coping, and well-being variables. A stress and coping model guided the study. Fifty-eight caregivers participated during the first four months caregiving. Caregiver and stroke survivor demographic and well-being data were collected during acute rehabilitation. Three problem-related themes emerged: interpersonal disruptions (IPD), sustaining the self and family (SS&F), and stroke survivor functioning (SF). Although SS&F problems were most frequent, IPD problems were rated most stressful and lowest in coping effectiveness. A component of emotional distress, either anxiety or depression, was related significantly ($p < .05$) to the stress level of each problem theme. Counseling on problem solving strategies may improve caregiver well-being.

Keywords

stroke; caregivers; problems; stress; coping effectiveness

Introduction

The abrupt onset of a stroke often results in sudden life changes, not the least of which is alteration in the roles and responsibilities of the stroke survivor and the caregiver. Generally, the caregiver assumes multiple responsibilities and the survivor temporarily or permanently relinquishes important roles and responsibilities. Such changes have potential to impact the

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

physical and psychosocial well-being of both members of the stroke survivor-caregiver dyad. High levels of depression have been reported for stroke caregivers. Research indicates that stress, behavior and cognitive problems, family functioning or family conflict, and patient function are related to depression and other negative outcomes (Clark, Dunbar, Shields, Viswanathan, Aycock, & Wolf, 2004; King, Carlson, Shade-Zeldow, Bares, Roth, & Heinemann, 2001; Kotila, Numminen, Waltimo, & Kaste, 1998; Schulz, Tompkins & Rau, 1988; Teel, Duncan, & MinLai, 2001). Thus, it is important to understand the nature, stressfulness, and effectiveness of coping with family caregiver problems at different times during the trajectory of recovery.

Stroke caregivers have identified the hospitalization period following a stroke and the transition to home life as most difficult during the first two years of caregiving (King & Semik, 2006). However, little is known about the stressfulness of specific problems that contributed to negative outcomes during those times. A number of studies assessed stroke caregiver problems, but few focused on problem stress levels or self-efficacy of problem management during the transition to home care. Nevertheless, wide-ranging problems have been described during the first three to four months of caregiving. Among survivor-related problems were cognitive, language, and functional impairments, emotional issues, safety, and non-compliance (Davis & Grant, 1994; Grant, Glandon, Elliott, Newman Giger, & Weaver, 2004; MacKenzie, Perry, Lockhart, Cottee, Cloud, Mann, 2007; Pierce, Steiner, Hicks, Holzaepfel, 2006).

Caregivers have reported personal problems such as fatigue, emotional distress, restricted social life, changes in family life, relationship difficulties, balancing responsibilities, and obtaining services (Bugge, Alexander, & Hagen, 1999; Grant et al., 2004; Ilse, Feys, deWit, Putnam, & deWeerd, 2008; MacKenzie et al., 2007; Periard & Ames, 1993). They also reported insufficient information and skills, uncertainty about recovery, lack of support from clinicians, and financial issues (Davis & Grant, 1994; King & Semik, 2006). Most studies used qualitative designs and were comprised of small samples of 10 to 22 caregivers.

Researchers reported strain in 25% to 28% of caregivers during the first 3 to 4 months caregiving; but problem stress levels were not assessed (Bugge et al., 1999; Ilse et al., 2008). Two studies conducted six months or longer post-discharge examined problem stress level and/or self-efficacy. The first study included subjects caregiving 8 to 12 months and examined only survivor care-related problems (Haley, Allen, Grant, Clay, Perkins, & Roth, 2009). Survivor's emotions, incontinence, and memory issues were most stressful. Hartke and King (2002) reported that the most stressful problems (survivor noncompliance and emotions, and caregiver interpersonal concerns) were among the least effective. The mean time caregiving was over two years.

The major purposes of the current study were: (1) to identify the types and frequency of caregiving problems during acute rehabilitation and the first three to four months post-discharge and (2) to examine the stress level and coping effectiveness for specific problems. The secondary purposes were: (1) to examine changes in problem type and frequency, and stress and effectiveness levels over time, and (2) to identify relationships between problem stress levels and personal, survivor illness, coping, and well-being variables. The participants were a sub-sample of caregivers of stroke survivors who were participating in a problem-solving intervention study.

Conceptual Model

The Moos and Schaefer Model of the Coping Process (Moos & Schaefer, 1986) provided the conceptual framework for the parent study. The model proposes that environmental (life stressors, social resources) and personal factors (demographics) influence life crises and

transitions (e.g., the stroke event; caregiver problems). These combined factors influence health and well-being directly and indirectly through mediators such as coping strategies.

Methods

We used a longitudinal, mixed methods descriptive design to obtain caregivers' perceptions about their stressful problems over time. The qualitative findings were based on descriptions of problems provided during the intervention sessions. Quantitative data resulted from caregivers' numeric ratings of stress and effectiveness ratings. Problems identified were often associated with the topic of the intervention session, such as self-care, dealing with depression, and the impact of the stroke on family roles and responsibilities.

Variables and Measures

Guided by the conceptual model, we assessed caregiver and survivor personal factors, survivor function, caregiving problems, coping variables, and well-being outcomes.

Data Forms were developed to collect caregiver and survivor demographic data. Of these, caregiver sex and race, which are commonly associated with well-being, were included in the correlational analysis. Stroke Survivor Functional status was measured using the Functional Independence Measure (FIM), which assesses severity of disability using an 18 item, 7-point scale; higher scores represent greater independence (Granger, Hamilton, Sherwin, 1986). The FIM has adequate internal consistency for the motor and cognitive scales (Granger et al.). Data were retrieved from the stroke survivors' medical records.

Problem identification and coping

Counselors used the Record of Treatment Sessions (RTS) to document the most pressing problems. The coping variables, stress appraisal and coping effectiveness, were rated on a five point scale ranging from 1 "Not at All" to 5 "Very" (Toseland, Rossiter, & Labrecque, 1989). Higher scores reflected greater stress and effectiveness. Problem-Solving coping was measured using the Social Problem Solving Inventory-SPSI-R short form (D'Zurilla, Nezu, & Maydeu-Olivares, 1996). This 25-item scale contains subscales that measure problem-orientation (e.g., positive (PPO) and negative (NPO)) and problem-solving styles. Higher scores reflect unhealthy problem solving. The NPO scale was used in the current study. Internal consistency is adequate (.72 to .85). Validity has been supported by correlations with depression and anxiety in the expected directions (D'Zurilla et al.).

Well-Being Outcomes

The Centers for Epidemiological Studies – Depression (CES-D) was administered as a screening measure for depressive symptoms (Radloff, 1977). The CES-D measures the frequency and severity of 20 depressive symptoms experienced during the past week. The possible range of scores is 0 to 60; higher scores reflect greater symptom severity. Alpha coefficients in community subjects ranged from .85 to .90; high correlations with other measures of depression were reported (Radloff).

Perception of Life Changes was measured using the Bakas Caregiving Outcomes scale (BCOS), which measures changes in social functioning, subjective well-being, and somatic health (Bakas & Champion, 1999). The 16-items with a 7-point response set are summed for an overall score that reflects how the caregiver's life changed. Reliability and content and construct validity are strong (alphas = .77 to .90). Higher scores represent more positive life change.

Anxiety was measured using the Profile of Moods Scale short form (POMS; McNair, Lorr, Droppleman, 1992). This 30 item scale contains six subscales. The Tension-Anxiety subscale ($\alpha=.86$ to $.88$) measures feelings ranging from intense to mild. Predictive, construct, and concurrent validity have been reported (McNair et al.). Higher scores reflect greater anxiety.

Caregiver Preparedness was assessed using the Preparedness for Caregiving Scale (PCS), which measured caregiver's perception of their preparedness to manage the tasks and stresses of caregiving (Archbold, Stewart, Greenlick, & Harvath, 1990). The PCS is an 8-item, 5-response option scale with higher scores representing greater preparedness. The potential range of scores is 0-4. Alpha coefficients, tested over time with multiple samples, ranged from $.67$ to $.92$.

Family functioning was assessed using the General Functioning Scale of the McMaster Family Assessment Device (FAD; Epstein, Baldwin, Bishop, 1983). This 12 item, 4-point subscale assesses overall health/pathology of the family. The range of scores is 1 to 4; higher scores reflect less healthy functioning. Concurrent and predictive validity have been reported; coefficient alpha was $.92$ (Epstein et al.).

Procedures

Institutional Review Board approval was provided by the four rehabilitation sites from which participants were recruited. Following informed consent, caregivers were screened for a CES-D depression score of ≥ 10 and met the following criteria: aged 21 or older, primary caregiver for and living with an adult survivor of a recent stroke who was planning to return home, sufficient hearing to engage in counseling sessions and assessments, telephone access, and English speaking. Caregivers were excluded if they were in therapy or a stroke support group.

Baseline data were collected for demographic, illness, coping, and well-being data. Caregivers discussed their most pressing problems during intervention sessions, which were audio-taped. Stress and effectiveness ratings were not collected when session goals did not include problem-solving. Problem descriptions and stress and effectiveness ratings were retrieved from the RTS forms. Problem-related quotations were transcribed from the audio-tapes.

Analysis

Descriptive statistics were computed for caregiver variables and problem data. Problems and stress and effectiveness ratings were analyzed for the 10 sessions, and separately for the first 4 sessions and last 6 sessions to compare early and later problem findings. Early problems were those reported during the first 4 intervention sessions (immediately pre-discharge up to 2 to 5 weeks post-discharge). Later problems were reported during the final six sessions (up to 16 weeks post-discharge).

We used content analysis to code and categorize problems, which had been entered into the data-base (Patton, 1990). The problems were coded independently by two investigators for 20 caregivers. Then, the first author rated the first 20 cases; and compared the ratings with those of the other investigators. Differences were discussed until 100% agreement was reached. Given the similarity of the initial problem codes to our earlier study of spousal caregivers (Hartke & King, 2002) we used this prototype of problem categories to guide subsequent analyses. The first author identified patterns of similarity between problem categories to develop themes which were verified by the other investigators. Pearson correlation coefficients were computed to examine relationships between the stress themes and caregiver sex and race, problem orientation coping, depression, life changes, anxiety,

caregiver preparedness, and family functioning, depression, caregiver preparation, life change, problem orientation, and survivor function.

Results

Sample

The sample consisted of 58 caregivers, who had been randomized to the treatment arm of the study. The majority was female (78%), Caucasian (74%), and spouse of the survivor (63%). Table 1 shows demographic statistics for the caregiver-survivor dyads. On average, the stroke survivors had high impairment levels, requiring moderate to maximal assistance.

Categories of Problems and Theme Development

Fifteen problem categories and definitions were identified. Three themes emerged, consisting of problems related to: (a) sustaining the self and family (King and Semik, 2006), (b) stroke survivor functioning, and (c) interpersonal disruptions (Hartke and King, 2002). Sustaining the self and family was comprised of well-being concerns. Survivor functioning problems included survivor emotional/physical concerns and caregiving demands. Interpersonal disruptions included personal problems such as relationship difficulties. The themes, problem categories, and descriptive statistics are shown in Table 2 for the total study period. Table 3 displays the data over time. Medians were used to examine problems over time because of reduced frequencies.

The frequency of problem categories varied widely and many problems were raised more than once. The most frequent was caregiver role demand. Caregivers perceived varying levels of stress and a range of effectiveness in managing problems. The average stress score for the problems comprising the interpersonal disruption theme was the most stressful problem theme for the total study period ($M = 4.22 \pm .72$; moderately stressful) compared with a mean of $4.01 \pm .78$ (moderately stressful) for sustaining the self and family, and 3.71 ± 1.01 (fairly stressful) for stroke survivor functioning. Caregivers were less effective in managing interpersonal disruptions $M = 2.64 \pm 1.12$ (a little effective), compared with survivor functioning $M = 3.60 \pm 1.15$ (fairly effective) and sustaining the self and family $M = 3.85 \pm 1.22$ (fairly effective).

Problem themes, associated stress and coping effectiveness

Theme 1: Interpersonal disruption problems were moderately to very stressful and several decreased in effectiveness over time. *Dyadic relationship problems* included poor dyadic communication patterns, caregiver frustration with role reversal, and intimacy issues. Although infrequent, this category of problems was the most stressful and among the least effective during early and later times.

Interpersonal conflict was the third most frequent problem facing caregivers, occurring as often during early and later sessions. Median stress levels changed from moderate to very stressful over time. Although some problems related to the health care system, problems with family members or friends were more common. A woman caring for her sister said “People take advantage of me, I don't know if I made them think that way, but it's a hard thing.” A mother indicated, “Everybody around you feels like you should be grateful for what you have (that her daughter survived), but they're not in our situation.”

Although *social involvement problems* were infrequent, they were moderately stressful at each time and caregivers were “not at all” to “a little” effective. Examples of losses expressed by caregivers were “losing my lifestyle”, and missing family rituals and enjoyable activities.

During the first weeks, *survivor negativity* was identified in activities such as demanding behaviors, verbally abusive language, irritability, and complaining. Behaviors that were reported during the last 6 weeks of the intervention included requests for unnecessary care and not trying hard enough. As one husband said, “she can be impatient when it comes to helping her” Negativity was uncommon, was moderately stressful initially, improved with time, and showed decreased effectiveness over time.

Theme 2: Sustaining the self and family. Sustaining the self and family problems were common. *Financial* problems such as loss of insurance and decreased income, and worries about future finances were stressful and common at both times. The stress of managing finances and transportation costs for outpatient therapy were mentioned in later weeks.

A common source of distress during both time frames (e.g., sessions 1-4 and 5-10) was *finding time* for self-care and to get everything done, and balancing time between work, other family members, and caregiving responsibilities. Time-related problems were moderately stressful over all times.

Dealing with the *caregiver's own emotions* was common and moderately stressful across time. Caregivers dealt with a range of emotions from feeling guilty about wanting time for themselves to feeling resentful, overwhelmed, worried, or depressed. For several, staying hopeful, yet realistic, was difficult. A husband said: “...things are starting to level out. That can be discouraging, and a little less hopeful because she was making progress by leaps and bounds.”

Anxious vigilance was noted in statements about worry about the survivor's safety, (e.g., fear of falls) and the meaning of symptoms. Later, caregivers worried about the survivor's desire to return to work and the balance between quality of life and controlling stroke risk factors. Anxious vigilance was fairly stressful and equally common during early and later weeks.

Caregivers identified *uncertainty* as often during the early and later weeks. Early concerns were related to if and when recovery would occur. Several caregivers wondered how long the situation would last. Later concerns were more specific, “If recovery in using his arm does not occur, will it be a burden or will he adapt?” On average, uncertainty was fairly stressful.

Caregiver health problems were the least stressful. Inadequate sleep and worry about their current or future health were the focus of health concerns

Theme 3: Stroke Survivor Functioning. *Specific impairment* problems were more common later and were moderately stressful. Most specific impairment problems were related to cognitive/communicative issues, survivor symptoms and health, functional losses, and actual falls. A plateau of function was bothersome to several caregivers during the later weeks of the study. As one husband stated, “I keep thinking her hand is going to get better..... She can't take her clothes off, or go to the bathroom – if she could just do a few of those things...”

Returning control to the survivor emerged as a problem during later sessions; the median was very stressful. As one caregiver said, “With someone who is gravely ill you kind of take over and that's not right. ... He said to me, ‘why do you have to arrange everything?’ and that really put me in my place.”

Caregiver role demand problems were similar in frequency during early and later sessions, and were moderately stressful with fair coping effectiveness. Role demands included providing physical assistance, discharge planning, acquiring resources, and dealing with

changes in family decision-making. One caregiver said, "I make decisions on my own, but not this kind. I tended to rely on him (SS) for big decisions." Later caregiver demands were similar to the first weeks, excepting greater emphasis on structuring the role of family members in assisting with care. As one caregiver said,

I told my sister, I'm overwhelmed, can you take over scheduling? It's not that I don't want to talk to them; it's just the anxiety that when I email or text or call, they don't get back to me for hours

The types of *noncompliance* problems and their stress levels were similar across early and later times; however, coping effectiveness decreased. Concerns included the survivor not following therapy recommendations, and non-adherence to medical regimens. Noncompliance was mentioned more frequently during the first four sessions than later ones (26 times vs. 11).

Early in caregiving, *survivor emotions* that troubled caregivers included the survivor feeling self-conscious and not wanting to be seen, or appearing depressed, anxious, or frustrated. Later, concerns included worry that the survivor would feel scared when alone, the survivor's distress over feeling abandoned by friends, supporting the survivor in making lifestyle changes, and the survivor's loss of family roles. Problems related to the survivor's emotions were similarly frequent and among the least stressful problems during early and later times.

Correlations between problem theme stress and study variables

Table 4 contains the descriptive statistics and alpha coefficients for the measures. Correlations between themes and study variables are shown in Table 5. Survivor functioning stress was correlated positively with anxiety, negative problem orientation, and with being female, and was correlated negatively with preparation for caregiving and life changes. Interpersonal disruption stress was related positively to anxiety and to White race. Stress associated with sustaining the self and family was related positively to depression.

Discussion

Taken as a whole, these data underscore the need to support caregivers during the transition to home care. Life disruptions occur instantly and result in multiple problems with a range of stressfulness and coping effectiveness that can result in chronic stress (Bugge, Alexander, & Hagen, 1999). The findings provide evidence of the changing nature of problems over time as survivors recover and caregivers acclimate to their new role. Among the three themes, interpersonal disruptions were most stressful and caregivers were least effective in managing these problem. These findings illustrate that the stresses encountered by caregivers are not always intuitively obvious. The problems of care provision may be secondary to the strain of negotiating changes and tensions in relationships within and around the caregiving dyad.

The most common problems in the current study: caregiving demands, finding time, and interpersonal conflict contrast with a recent report that the most frequent problems four to six weeks post-discharge were handling mood fluctuations, feeling tired, and restricted social life (MacKenzie, Perry, Lockhart, Cotter, Cloud, & Mann, 2007). In contrast to MacKenzie et al.'s study and others, which used structured scales (Bugge et al, 1999; Ilse et al., 2008), we used an open-ended question to identify pressing problems. Thus, we might have missed problems that were not highly stressful, and they may have missed problems that were unique to a smaller number of caregivers. Given the variability in samples and data collection techniques, it is remarkable how much similarity there can be in identified problems.

Most problems are similar to those reported by Hartke and King (2002) in a study of long-term spousal caregivers; however, caregiver emotions and finding time were more frequent in our study. Issues around organizing tasks and family life after the sudden onset of a stroke may contribute to the increased frequency of these problems in new caregivers. Our findings contrast with those of Grant, Glandon, Elliott, Newman, and Weaver's (2004), which indicated that safety was the most frequent problem, but are similar to those of Pierce et al. (2006) findings on change over time. Pierce et al. reported that therapy participation problems decreased, but balancing responsibilities and living with physical limitations did not change in frequency. In contrast to Pierce's findings that most problems were patient-focused the majority of problems in our study were caregiver-focused. Bakas, Austin, Okonkwo, Lewis, and Chadwick (2002), reporting on caregivers in the role up to 6 months, also reported that caregiver-focused problems were infrequent. Patient emotions/behaviors and information needs were most common.

Two problems may be unique to the current study. The first is returning control of life to the survivor, which emerged during later sessions. The second, related to patient emotions, is the survivor not wanting to be seen in public. The stroke survivors struggled to adapt, not only to changes in functioning, but also to their perceptions of how others view them.

Researchers have reported strain for 30% to 86% of caregivers with 25% reporting considerable strain (Bugge et al., 1999; Ilse et al., 2008). Our findings indicate that 98% reported one or more problem, which was fairly to very stressful. The fact that caregivers were enrolled in a stress management/problem solving study and were screened for risk for depression may contribute to higher levels of stress in this sample. Excepting specific impairments, the most stressful problems are related either to sustaining the self and family or interpersonal disruptions. Each of the most stressful problems was low in coping effectiveness (dyadic relationship, interpersonal conflict, financial concerns, finding time, social involvement). Hartke and King (2002) and Periard and Ames (1993) also found that interpersonal concerns, time issues, and feeling confined were major problems.

Some stress ratings, particularly survivor negativity, were lower during later sessions. Potential explanations for the change from moderately stressful to a little stressful include improvement in the survivors' behaviors during the natural course of recovery, improved caregiver understanding of behaviors and ways of coping, and caregiver's improved management of their own emotional reactions to behaviors.

Caregiver effectiveness was lower for many problems during the later weeks. Most interpersonal disruption problems increased in stress; effectiveness improved slightly or not at all. This finding underscores the need to assess caregivers throughout the caregiving trajectory. Three to four months is probably insufficient to accept and compensate for complex problems.

Although several variables are correlated with the themes, the measures of functional status (FIM) and family functioning were not related to any thematic stress rating. Poorer preparation for caregiving, negative view, more negative life change, greater anxiety, and female sex were related to survivor functioning stress. Bugge et al. (1999) also found that female caregivers experienced greater strain one month post-stroke. Interventions to reduce the stress of specific impairments and role demands would benefit caregivers troubled by functional problems. Additionally, either anxiety or depression was correlated with each of the three themes. Stress can be exacerbated by negative emotions, which interfere with effective problem-solving (Nezu, Wilkins, & Nezu, 2004). Alternatively, dysfunctional problem-solving is related to greater depression and anxiety (Kant, D'Zurilla, & Maydeu-

Olivares, 1997). Stress may be decreased by interventions to decrease depression and anxiety or to improve problem-solving.

Limitations of the study include that problem identification was part of a problem-solving intervention, which may have affected perception of problems and related stress as well as how stress and coping effectiveness ratings changed as the intervention progressed. As noted above, the results also are influenced by the form of data collection. Future studies may benefit from use of a hybrid format in which the caregiver first has the open ended opportunity to identify issues followed by using a list of common problems to assure more comprehensive data collection.

Implications for practice. The range of problem types suggests that family education and discharge preparation that focuses exclusively on concrete care tasks, such as personal care, medication management, safety recommendations, and exercise programs, is short-sighted. Family instructions should include a discussion of behavioral issues and indirect life style and interpersonal disruptions that can be a source of considerable stress. Helping families develop an awareness of and confidence in solving these types of problems is the challenge for clinicians. Stress management techniques, such as relaxation training, may help caregivers to combat stress during the first weeks post-discharge when they assume 24 hour responsibility. Coaching effective communication skills may help offset interpersonal conflicts experienced by caregivers. Caregivers also may benefit from identifying potential support system resources (e.g., family members, religious or community organizations) and specific tasks which helpers could assume (i.e., grocery shopping, driving the survivor to therapy). Given the stress associated with changes in relationships and with interpersonal concerns, forming caregiver support groups (in-person or online) or other systems to help caregivers form connections with one another may be beneficial.

Acknowledgments

This work was supported by the National Institute of Nursing Research #5RO1NR009077 (Rosemarie B. King, PI). We wish to thank the caregivers who graciously gave of their time and energy to participate in this study. We also thank Florence Denby, MS, CRRN; Sylvia A. Duraski, MS, ANP-BC, CRRN, and Patrick Semik, B.A. for their assistance with this study.

REFERENCES

- Archbold PG, Stewart BJ, Greenlick MR, Harvath T. Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing and Health*. 1990; 13:315–384.
- Bakas T, Austin JK, Okonkwo KF, Lewis RR, Chadwick L. Needs, concerns, strategies, and advice of stroke caregivers the first 6 months after discharge. *Journal of Neuroscience Nursing*. 2002; 34(5): 242–251. [PubMed: 12391740]
- Bakas T, Champion V. Development and psychometric testing of the Bakas Caregiving Outcome Scale. *Nursing Research*. 1999; 48:250–259. [PubMed: 10494909]
- Bugge C, Alexander H, Hagen S. Stroke patients' informal caregivers: Patient, caregiver, and service factors that affect caregiver strain. *Stroke*. 1999; 30:1517–23. [PubMed: 10436093]
- Clark PC, Dunbar SB, Shields CG, Viswanathan B, Aycok DM, Wolf SL. Influence of stroke survivor characteristics and family conflict surrounding recovery on caregiver's mental and physical health. *Nursing Research*. 2004; 53:406–413. [PubMed: 15586137]
- Davis LL, Grant JS. Constructing the reality of recovery: Family home care management strategies. *Advances in Nursing Science*. 1994; 17:66–76. [PubMed: 7840548]
- D'Zurilla, TJ.; Nezu, AM.; Maydeu-Olivares, A. Social problem-solving inventory-revised. State University of New York at Stony Brook; Stony Brook: 1996.
- Epstein NB, Baldwin LM, Bishop DS. The McMaster Family Assessment Device. *Journal of Marital and Family Therapy*. 1983; 9:77–84.

- Granger, CV.; Hamilton, BB.; Sherwin, FS. Guide for the use of the uniform data set for medical rehabilitation. Project Office, Department of Rehabilitation Medicine, Buffalo General Hospital; Buffalo: 1986.
- Grant JS, Glandon GL, Elliott TR, Newman Giger J, Weaver M. Caregiving problems and feelings experienced by family caregivers of stroke survivors the first month after discharge. *International Journal of Rehabilitation Research*. 2004; 27:105–111. [PubMed: 15167107]
- Haley WE, Allen JY, Grant JS, Clay OJ, Perkins M, Roth DL. Problems and benefits reported by stroke family caregivers: Results from a prospective epidemiological study. *Stroke*. 2009; 40:1–5. [PubMed: 19008466]
- Hartke RJ, King RB. Analysis of problem types and difficulty among older stroke caregivers. *Topics in Stroke Rehabilitation*. 2002; 9(1):16–33. [PubMed: 14523720]
- Ilse IB, Feys H, de Wit L, Putman K, de Weerd W. Stroke caregivers' strain: Prevalence and determinants in the first six months after stroke. *Disability and Rehabilitation*. 2008; 30(7):523–530. [PubMed: 18365864]
- Kant GL, D'Zurilla TJ, Maydeu-Olivares A. Social problem-solving : A mediator of stress-related depression and anxiety in middle-aged and elderly community residents. *Cognitive Therapy and Research*. 1997; 21(1):73–96.
- King RB, Carlson CE, Shade-Zedlow Y, Bares KK, Roth EJ, Heinemann AW. Transition to home care after stroke: Depression, physical health, and adaptive processes in support persons. *Research in Nursing & Health*. 2001; 24:307–323. [PubMed: 11746061]
- King RB, Semik PE. Stroke caregiving: Difficult times, service use, and needs during the first two years. *Journal of Gerontological Nursing*. 2006; 32(4):37–44. [PubMed: 16615711]
- Kotila M, Numminen H, Waltimo O, Kaste M. Depression after stroke: Results of the FINNSTROKE Study. *Stroke*. 1998; 29:368–372. [PubMed: 9472876]
- McNair, DM.; Lorr, M.; Droppleman, LF. Edits manual for the profile of mood states (revised). Educational and Industrial Testing Service; San Diego: 1992.
- MacKenzie A, Perry L, Lockhart E, Cottie M, Cloud G, Mann H. Family carers of stroke survivors: needs, knowledge, satisfaction, and competence in caring. *Disability and Rehabilitation*. 2007; 29(2):111–121. [PubMed: 17364762]
- Moos, RH.; Schaefer, JA. Life transitions and crises: A conceptual overview.. In: Moos, RH., editor. *Coping with life crises: An integrated approach*. Plenum Press; New York: 1986. p. 1-28.
- Nezu, AM.; Wilkins, VM.; Nezu, CM. Social problem solving, stress, and negative affect.. In: Chang, EC.; D'Zurilla, TJ.; Sanna, LJ., editors. *Social problem solving: Theory, research, and training*. American Psychological Association; Washington, D.C.: 2004. p. 49-65.
- Patton, MQ. *Qualitative evaluation and research methods*. 2nd ed.. Sage; Newbury Park: 1990.
- Periard ME, Ames BD. Lifestyle changes and coping patterns among caregivers of stroke survivors. *Public Health Nursing*. 1993; 10(4):252–256. [PubMed: 8309893]
- Pierce L, Steiner V, Hicks B, Holzaepfel AL. Problems of new caregivers of persons with stroke. *Rehabilitation Nursing*. 2006; 31(4):166–172. [PubMed: 16789675]
- Radloff LS. The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*. 1977; 3:385–401.
- Schulz R, Tompkins CA, Rau MT. A longitudinal study of the psychosocial impact of stroke on primary support persons. *Psychology and Aging*. 1988; 3(2):131–141. [PubMed: 3268251]
- Teel CS, Duncan P, MinLai S. Caregiving experiences after stroke. *Nursing Research*. 2001; 50:53–60. [PubMed: 19785245]
- Toseland RW, Rossiter CM, Labrecque MD. The effectiveness of peer-led and professionally-led groups to support family caregivers. *Gerontologist*. 1989; 29:465–471. [PubMed: 2521104]

Table 1

Demographic Characteristics of Caregivers and Stroke Survivors (N = 58)

Variables	Caregiver		Stroke Survivor	
	N	Percent	N	Percent
Race: White	38	65.5	37	64.9
African American	12	20.7	13	22.8
Hispanic: White	3	5.2	5	8.6
Black	0	0	0	0
Asian	2	3.4	1	1.8
Other	3	5.2	1	1.8
Sex				
Female	45	77.6	25	43.1
Male	13	22.4	33	56.9
Relationship to Survivor				
Spouse	36	62.1	36	62.1
Non-spousal	22	37.9	22	37.9
Education: HS or greater	51	87.9	46	83.6
Employment				
Full or part-time	34	58.6	27	48.2
Unemployed/retired	24	41.4	29	51.8
	Mean	SD	Range	
Age: Caregiver	52.4	15.0	24 - 84	
Age: Stroke Survivor	58.7	16.3	22.2 – 85.9	

Note. Survivor race, n = 57; Survivor employment, n = 56.

Table 2

Problem Frequencies, Themes, and Stress and Effectiveness Levels over all Times

Theme and related problem	Number	Stress Mean (SD)	Effectiveness Mean (SD)
Interpersonal disruptions			
Dyadic relationship	11	4.80 (.45)	2.40 (1.14)
Interpersonal conflict	56	4.38 (.68)	3.06 (1.24)
Social involvement	10	4.00 (.71)	2.00 (.71)
Survivor negativity	17	3.64 (.99)	3.00 (1.38)
Sustaining the self and family			
Financial concerns	34	4.26 (1.18)	2.67 (1.17)
Time management	67	4.06 (.81)	3.34 (1.02)
Caregiver emotions	42	3.97 (.84)	2.83 (1.08)
Anxious vigilance	37	3.78 (.80)	3.60 (.97)
Future uncertainty	22	3.56 (1.02)	3.22 (1.20)
Caregiver health	8	3.28 (1.50)	2.57 (1.27)
Survivor function			
Specific impairment	32	4.00 (.90)	3.63 (1.08)
Returning control	6	3.90 (1.60)	2.80 (.84)
Caregiver role demands	85	3.79 (1.09)	3.39 (1.07)
Noncompliance	38	3.66 (1.32)	2.89 (1.15)
Survivor emotions	21	3.38 (1.15)	3.51 (1.40)

Note. Problems are ordered from high to low stress level within each theme.

Table 3

Problem Frequency, Stress, and Coping Effectiveness During Sessions 1 to 4 and 5 to 10

Problem type	Weeks 1 to 4						Weeks 5 to 10							
	N	Stress		Effectiveness		N	Stress		Effectiveness					
		Md	SD	M	SD		Md	SD	M	SD				
Dyadic relationship	3	5.0	4.1	.83	3.0	3.0	.82	7	4.0	3.8	.93	3.0	2.6	1.3
Interpersonal Conflict	28	4.0	4.2	.82	4.0	4.2	1.1	27	5.0	4.4	.73	3.0	3.2	1.1
Social involvement	4	4.0	3.7	.58	2.0	2.3	.58	5	4.5	4.5	.71	1.5	1.5	.71
Survivor negativity	9	4.5	4.2	.96	4.0	3.5	1.7	8	2.5	3.2	1.2	3.0	3.0	.35
Financial	18	5.0	4.6	.65	3.0	2.7	1.2	15	4.5	3.8	1.4	3.0	2.9	1.1
Time	31	4.0	4.1	.77	3.0	3.2	.95	35	4.0	4.0	.89	3.0	3.4	1.2
Caregiver emotions	19	4.0	4.1	.83	3.0	3.0	.82	22	4.0	3.8	.83	3.0	2.6	1.3
Anxious vigilance	18	4.0	3.8	.94	4.0	3.9	.77	19	4.0	3.9	.66	3.0	3.3	1.1
Future uncertainty	11	3.8	3.8	1.1	3.5	3.5	.70	9	4.0	3.5	1.2	3.0	3.1	1.3
Caregiver health	3	3.5	3.5	.71	3.0	3.2	1.8	5	2.5	2.5	.71	3.0	2.6	1.5
Specific impairment	13	4.0	4.1	.93	4.0	3.5	1.3	19	4.0	4.0	.92	3.5	3.6	.94
Returning control*	0							6	5.0	3.9	1.6	3.0	2.8	.84
Caregiver role demands	44	4.0	3.9	1.0	4.0	3.3	1.3	41	4.0	3.9	1.1	3.5	3.5	1.0
Noncompliance	26	4.0	3.6	1.4	3.0	3.0	1.0	11	4.0	3.8	1.1	2.0	2.4	1.5
Survivor emotions	9	3.0	3.2	1.4	3.2	3.2	1.2	11	3.0	3.2	1.1	4.0	3.8	1.4

* Returning control was not reported until weeks 5 to 10.

Table 4

Descriptive Statistics: Survivor Illness, Coping, and Well-Being Variables (N= 58)

Measure	Mean	Stand. Dev.	Alpha
Survivor functional status	48.16	21.00	.90
Negative problem orientation	5.06	4.53	.72
Depression	23.75	9.87	.91
Life change	53.22	10.06	.87
Anxiety	7.52	4.88	.83
Preparedness for caregiving	2.42	.74	.84
Family functioning	1.92	.40	.83

Table 5

Correlations: Theme Stress Levels and Personal, Illness, Coping, and Well-being

Theme	ANX	PREP	FAD	NPO	BAKAS	CESD	FIM	SEX	RACE
SS&F	.237	-.152	.149	.248	-.092	.292*	-.111	-.260	.007
IPD	.410*	.080	.112	.112	-.139	-.194	.021	-.062	.384**
FUNC	.374**	-.346*	.130	.305*	-.320*	.273	-.182	-.375**	.019

Note. SS&F =Sustaining self and family, IPD = Interpersonal Disruption, FUNC=Stroke survivor functioning. ANX = anxiety, PREP = Preparedness for caregiving, FAD = family adjustment device, NPO = Negative problem orientation, BAKAS = Bakas caregiving outcomes scale (life change), CES-D = Centers for epidemiologic studies-depression scale, FIM = Functional independence measure. Sex 0 = female, 1 = male; race 0 = nonwhite, 1 = White.

*
p < .05

**
p < .01