Stress Experienced by Stroke Survivors and Spousal Caregivers During the First Year After Discharge from Inpatient Rehabilitation

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Abstract

Purpose—This study describes levels of stress in stroke survivors and spousal caregivers and identifies predictors of stress in couples during their first year at home.

Method—The perceived Stress Scale (PSS) was administered to 159 stroke survivors and caregivers at discharge, 3, 6, 9, and 12 months. Other variables tested included stroke survivor function (FIM), health status, mutuality, stroke impact (SIS), caregiver coping (F-COPES), support (MOS Social Support Survey), and preparedness. Repeated measures analyses of PSS scores were conducted with linear mixed models for stroke survivors and caregivers.

Results—PSS scores for stroke survivors and caregivers were positively correlated (p<.01). Scores decreased significantly over the year, but caregivers had higher scores initially and decreased less. Stroke survivor function was a significant predictor of stress for both survivors and caregivers. Preparation was the most powerful predictor of stress in caregivers, while mutuality was the strongest predictor for stroke survivors. Good health, social support and coping were associated with less stress.

Conclusions—Stress is increased by poor function and mediated by internal and external buffers including health, the dyadic relationship, coping ability and social support. More research using a dyadic research approach is needed to better understand stress within couples.

Keywords

stroke; cerebral vascular accident; stroke survivor; stress; coping; social support; preparedness; caregiver; spouse; mutuality

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INTRODUCTION

Stroke survivors and their caregivers confront individual and shared experiences that are unique and often unanticipated during the first year of recovery after stroke. Unlike many adult-onset chronic conditions, stroke survivors typically experience sudden and intense physical, cognitive, and behavioral changes.[1] Following discharge from the hospital, they are often assisted in their recovery by spouses and other family members. When spouses are available to provide at-home care, even low functioning stroke survivors, who may have otherwise been placed in nursing homes, may be discharged home.[2] Spousal caregivers have been shown to

be more susceptible to feelings of stress than other informal caregivers.[3] Increased stress may be related to the intense physical and psychological demands of caregiving on the caregiver's health.[4] As caregivers' well-being declines, so does the ability to provide adequate care for their stroke survivors,[5] placing both members of the dyad at risk for poor health.

Conceptual Model of Stress and Coping

The stress and coping process is commonly used to describe how individuals and families adapt to the stress of chronic illness. Lazarus and Folkman's stress and coping theory maintains that coping is a process by which the demands of a threat or challenge are made manageable.[6] The individual and family's appraisal of the threatening event and their problem solving and coping responses help to determine the impact of the stressor on their lives. Appraisal has two components: a) objective appraisal that represents the examination of a stressor to determine the nature and extent of the threat or challenge, and b) subjective appraisal that is the process in which a person or family assesses their capacity to manage the threat or challenge. This study posited that stroke survivor and spousal caregiver outcomes were a function of pre-existing vulnerabilities (i.e.,, age, gender, health, socioeconomic resources) and exposure to caregiving stressors (i.e., the stroke and its sequelae), and could be buffered by psychological and social resources. McCubbin and McCubbin's Double ABCX Model[7] hypothesized that these buffers (i.e., knowledge, preparation, attitudes, resources, and social support) could be manipulated and strengthened, so that, even in the face of an apparently overwhelming stressor, forces could be marshaled to preserve the person and family. In the case of a stroke, this approach maintains that certain mediating variables influence stroke survivors' and spousal caregivers' responses and adaptation to the stroke. One outcome of a stroke can be the stress that it produces. In this study, stress is defined as negative feelings of being unable to control or manage the problems and external events that occur in life.

Stroke Survivor Stress

From the onset of stroke recovery, even during hospitalization, the stroke survivor's environment changes in potentially stressful ways.[8] Effects of stroke can be as fundamental as limited mobility and the inability to perform activities of daily living (ADLs), and as transcendental as decreased participation in leisure activities [9, 10] and limitations on meaningful life roles.[10] Consistent with the Double ABCX Model, stroke survivors' outcomes have been known to depend on internal buffers, such as the their overall outlook on life, their attitudes regarding the stroke, and their ability to cope with the situation.[11] For many stroke survivors, recovery is accompanied by feelings of depression and irritability.[8, 12] Loss of autonomy caused by even a minor stroke may lead the stroke survivor to feel that he or she is a burden on the caregiver.[13] External buffers, such as social support and family dynamics have consistently been found to predict the nature of recovery.[14] The stroke survivor-caregiver relationship, sometimes referred to as connectedness, coherence, or mutuality, is one aspect of family function that seems to be predictive of stroke survivor stress and the degree of recovery experienced.[15] Recent analyses have also reported that physical function, emotional distress, feelings of sadness, and depression serve as predictors of stress in stroke survivors at the time of discharge home from inpatient rehabilitation,[2] but there are few longitudinal studies of stress in stroke survivors.

Caregiver Stress

Over a relatively short period of time, spousal caregivers must learn new skills, [16] while often simultaneously facing economic strain, [17] and attempting to cope with the symptoms exhibited by the stroke survivor. Not surprisingly, caregivers experience stress.[17, 18] Feelings of insecurity in one's ability to take on the caregiving role[19] can become even more stressful in the absence of social support.[20] Researchers have found stress to be physically and

psychologically taxing on caregivers of stroke survivors,[21] especially spousal caregivers in whom depression often coexists with stress.[22, 23] Schulz and Beach (1999) reported that spousal caregivers experiencing strain and worry about their spouses were at 63% higher risk of mortality within four years than their non-caregiver counterparts.[24]

Certain subgroups, including females, younger caregivers and people caring for more cognitively, behaviorally, and emotionally-affected stroke survivors are especially vulnerable to the effects of burn-out caused by stress.[5] Furthermore, younger caregivers with higher levels of education reported greater stress levels in a cross-sectional study of caregivers of brain tumor patients, whose neuron-physical symptoms resembled those of stroke survivors.[25]

Interaction Between Stroke Survivor and Caregiver Stress

While stroke survivors and caregivers experience stroke differently, research suggests that stress levels experienced by caregivers may be influenced by stroke survivors' characteristics and their level of recovery. Stroke survivor mental health and cognitive function,[26] stroke survivor depression,[22] the presence of aphasia,[27] and a greater degree of impairment [28, 29] have been linked to greater caregiver stress. Other researchers have observed that caregivers' perceptions of disease recovery, [30] perceptions of available social support, and the state of family dynamics [31] are also associated with caregiver stress. Furthermore, caregiver's perceived burden has not only been associated with caregiver stress,[32] but it has also been associated longitudinally with stroke survivor distress,[33] and can hinder the stroke survivor's recovery.[34] However, the caregiver's emotional distress and perception of the stroke survivor's ability may be more related to caregiver perceptions than to the stroke survivor's characteristics.[27, 30] Archbold, et al.[35] reported that caregivers who had positive relationships with their care-receivers experienced less strain because they found caregiving inherently meaningful. A strong sense of perceived caregiver-stroke survivor connectedness, coherence, or mutuality, appears to be related to low levels of stress in stroke survivors and caregivers. [36] Time may also serve as a mediating factor and should be considered in research that looks at outcomes of stroke survivors[37] and their caregivers. Little research has been reported on stress levels of stroke survivors and spousal caregiver dyads over time. Nor has there been research on the interaction between stroke survivor and caregiver stress or the predictors of stress in each member of the dyad.

Purpose

The purposes of this study were to (1) describe levels of stress, using the Perceived Stress Scale (PSS), in stroke survivors and spousal caregivers at discharge from inpatient rehabilitation and at 3, 6, 9, and 12 months post discharge, and to (2) identify predictors of stress among stroke survivors and their spousal caregivers during the first year after discharge from inpatient rehabilitation.

METHODS

Study Design and Sample Population

Committed to Assisting with Recovery after Stroke (CAReS) was a longitudinal study that followed stroke survivors and their spousal caregivers for twelve months following discharge home. Participants (n=159 couples) were recruited between November, 2001 and December, 2005 from five hospitals and rehabilitation centers that are part of a large medical complex in Southeast Texas.[38] Stroke survivors met the following inclusion criteria: incident stroke during the preceding 12 months, aged 50 or older, returning home from the hospital with a spouse or committed partner, living within 50 miles of the study site, able to speak and understand English, had a telephone, and both members of dyad agreed to participate in study. Participants were excluded who had severe global aphasia or psychiatric or physical conditions that would

interfere with their ability to participate in the study (e.g., dementia). CAReS was approved by the university's Institutional Review Board (IRB) and by the IRB committees of the health care systems from which patients were recruited.

Data Collection

Trained data collectors abstracted demographic and health-related data from the stroke survivor's inpatient chart prior to discharge. After the stroke survivor was discharged home, a trained research nurse interviewed stroke survivors and their spousal caregivers in their homes. Data were recorded on forms created by Cardiff Teleform software[39] and scanned directly into a Microsoft Access database. Data were collected following discharge and every three months thereafter for 12 months, giving a total of five data collection periods.

Instruments

A trained nurse researcher collected socio-demographic data on the spousal caregivers and confirmed the accuracy of the data abstracted from the hospital chart on the stroke survivor. Socioeconomic status was estimated using the four-factor Hollingshead's formula which considers the education and occupation of both members of the couple.[40] Additionally, the following seven instruments were administered at baseline and every three months thereafter, with the exception of Mutuality scale which was administered at baseline, six and twelve months.

The Perceived Stress Scale (PSS-10), [41] a 10-item scale, asked stroke survivors and spousal caregivers to rate the extent to which they have felt their life to be stressful during the past month. Item scores as rated on a 5-point scale (0 = never to 4 = very often) range from 0 to 40, with higher scores suggesting higher levels of stress.[42] The PSS has demonstrated good internal consistency (0.78), moderate correlations with other measures of appraised stress, and is consistent with the stress and coping model used in this study. The Cronbach's alpha coefficient for the PSS was 0.85 in this study.

The Mutuality Scale, a 15 item scale, measures the positive caregiving relationship between the caregiver and the care receiver.[35] Stroke survivors and spousal caregivers answered items on a 5-point scale (0=not at all to 4=a great deal). The total score is the sum of the individual items divided by the number of items answered with a possible range of 0–4. High scores indicate the relationship between caregiver and care receiver is characterized by love, shared pleasurable activities, common values, and reciprocity. Cronbach's alpha for caregivers' and stroke survivors' mutuality scales in this study were 0.94 and 0.92, respectively.

Self-Rated Health Status is a subjective measure of an individual's perceived health that has been shown to be a valid health status indicator.[43, 44] Stroke survivors and spousal caregivers were asked "How would you rate your health?"[43] They responded on a 5-point scale of (1) excellent, (2) very good, (3) good, (4) fair, and (5) poor.

Functional Independence Measurement (FIM) Scale, [45] an 18-item scale, measures the degree of independence in the stroke survivor on a 7-point scale (7-Complete Independence to 1-Total Assistance). The total scores range from 18–126 with higher scores representing more independent functioning. The FIM has been found to be a reliable measure of function for stroke survivors (Cronbach's alpha = 0.93) with inter-rater correlations ranging from 0.86 to 0.88.[45] Cronbach's alpha for the FIM was 0.95 in this study.

The Stroke Impact Scale (SIS) version 2[46] is a disease-specific quality of life measure that assesses the degree to which the physical, mental, and emotional changes due to stroke affect the survivor's quality of life. It includes 64 items in the following categories: extremity strength (4), memory and thinking (8), emotional health (9), ability to communicate (7), ADLs (12),

mobility (10), ability to use upper extremities (5), participation in activities (9), and a scale of 0–100 to rate their degree of recovery with 0 being no recovery to 100 being fully recovered. The 1-week test-retest reliability correlation coefficients for the 8 SIS domains ranged from .70 to .92 (except for the emotion domain which was .57). Reliability coefficients for the CAReS data at baseline ranged from .84 –.96 on all eight sub-scales.

The Medical Outcomes Study (MOS) Social Support Survey[47] was used to measure perceived social support in spousal caregivers. The first item on the scale assesses perceived structural support by asking the following question: "About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)?". The following 19 items appraise perceived functional support. Functional support items are divided into four sub-scales: tangible support, positive social interaction, affection, and emotional/ informational support. For each of the 19 items, caregivers responded on a 5-point scale (1-none of the time to 5-all of the time). Sub-scale scores are computed by averaging the scores on all items in the sub-scale. A total score is obtained by averaging the scores on all items in the sub-scales and the score for item 14 ("Someone to do things with to get your mind off of things"). Scores are transformed on a scale of 0–100 to aid in comparison by using the following formula: observed score − minus possible score divided by the maximum possible score − minus the minimum possible score. Higher scores indicate more support. Internal consistency for the overall functional support scale has been reported as .97 and ranging from .91 to .96 for the four subscales. In the present study, Cronbach's alpha for the four sub-scales ranged from 0.89 to 0.95.

Family Crisis Oriented Personal Evaluation Scales (F-COPES) [48] is a 30-item scale that measured coping behaviors in the spousal caregivers. Coping behaviors are grouped into 5 sub-scales that measure both the internal and external methods a family uses to handle difficulties and problems. After the four items that constitute the passive appraisal scale are reverse scored, the five subscales are combined to form a total score. The total scale ranges from 50–130 with a higher score indicating better problem solving and behavioral strategies. The reported total scale Cronbach's alpha is 0.86 and the test-retest reliability over 4–5 weeks is 0.81;[49] similar to the CAReS Cronbach's alpha of 0.84.

The Preparation for Caregiving Scale (PCS Shortened Version) [35] measures caregivers' sources and methods of learning, perception of preparation to care for physical and emotional needs, and preparation to arrange needed services. Spousal caregivers responded on a 1 to 4 scale (0-not at all prepared to 4-very well prepared). The overall score is computed by summing the responses and dividing them by the number of items answered; thus the total scores range from 0 to 4. The reported alpha coefficient was .72 at 6 weeks and .71 at 9 months. Cronbach's alpha for the CAReS study was 0.90.

Data Analysis

Descriptive statistics, including means, standard deviations, and percentages, were calculated for demographic variables and instrument values. Repeated measures analyses of Perceived Stress Scale (PSS) scores from baseline to 12 months were conducted with linear mixed models. [50] Separate models were developed for the stroke survivors and their spousal caregivers. The initial model for stroke survivors included all of the variables listed in Table 1 to determine which factors were significant predictors of stress score. For the caregiver model, a sequential method[51] was used to determine from the list of variables presented in Table 1 those factors that were significant predictors of the stress score. Demographic and other contextual variables were entered as a block to comprise the initial model. A second model was constructed by adding mediating variables (subscale scores from the F-COPES and MOS Social Support Scales and the total score from the Caregiver Preparedness scale) to those variables that were found to be significant predictors (p < .05) of stress in the initial model. The final models for

both the stroke survivors and their caregivers included only those variables with a p value < .05. All statistical analyses were performed using SAS for Windows, version 9.1.[52]

RESULTS

Profile of Participants

The socio-demographic profile of the study participants is shown in Table 2. The majority of stroke survivors were male (74.8%) and their mean age was 66.4; stroke survivors were, on average, about four years older than their caregivers (62.5 years). Forty-two percent of the sample were minorities, primarily African American and Hispanic, which is representative of the southwestern US. The socioeconomic status (SES) mean score calculated using occupation and education according to Hollingshead's formula[46] was 43.44 (SD=11.62, range 19.5–66) suggesting that the couples in this study came from diverse socio-economic backgrounds.

The majority (76%, n=116) of stroke survivors in this study had an infarction, 23% (n=35) had a hemorrhage and the remaining 1% had "other" types of strokes (i.e., arteriovenous malformation). Slightly more than half of the sample had a left hemisphere stroke (55%, n= 87), few participants had global or brain stem strokes (3% and 1%, respectively); the other 41% (n=64) experienced a right hemisphere stroke. Thus, the population in this study demonstrates the heterogeneity inherent in stroke survivors.

On average, stroke survivors were approximately three months post stroke at the time of their discharge baseline assessment ($\bar{X}$=89.87 days, SD= 77.74 days, range 12–405 days). The unusually long hospital stays represent individuals who experienced severe strokes with multiple complications, but were still eventually discharged home with their spouses. Accordingly, there was wide variation in the severity of the strokes experienced by this sample. Although the number of days since stroke varied widely in our sample, the length of time since the stroke was not associated with the PSS score for either the stroke survivors (p = .51) or caregivers (p = .76) at hospital discharge or at 3, 6, 9 or 12 months post-inpatient hospital discharge. Therefore, time since stroke was not included in the final models discussed below.

Variables that were significant in the final models are shown in Table 3 with their means (SD) and ranges. While the means for most variables fell in the moderate to high range, the ranges for all variables were very wide. Both stroke survivors and caregivers were similar in their perception of mutuality with the average scale score for both participants quite high. Interestingly, at baseline the caregiver's perception of their own health was slightly worse than the stroke survivor's perception of their own health (higher scores indicate poorer health). Even though the stroke survivors rated their general health, on average, as "good", their average perception of stroke recovery was only 52 % on a scale of 0 to 100%. Caregivers, on average, felt moderately well prepared to care for their spouses ($\bar{X}$=2.81 on a 4-point scale). All caregivers had at least one person available to them to provide support; the average number of persons available to provide support to the caregiver was 11.40, although the range was 1 to 52.

Perceived Stress Changes Over Time

Pearson product-moment correlations were computed to compare spousal caregiver and stroke survivor responses on the Perceived Stress Scale (PSS). The stress levels for both members of the dyad were positively correlated (r=0.348, p=0.0018). For both the stroke survivors and their spousal caregivers, mean scores on the PSS decreased over the course of follow-up (Table 4). The stroke survivors demonstrated an almost 2 point drop in stress scores, decreasing from a mean at baseline of 12.27 (SD=7.46, range 0–30) to a mean at 12 months of 10.47 (SD=7.30). The decrease in PSS scores for the caregivers was not as great, dropping from 14.00 (SD=7.25,

range of 0–33) at baseline to 13.21 (SD=7.12) at 12 months. Changes over time in PSS scores for both the stroke survivors and spousal caregivers were found to be significant by repeated measures analysis (p < .01 and < .03, respectively).

Predictors of Perceived Stress in Stroke Survivors

Analysis of stroke survivor PSS scores from discharge to 12 months indicated that higher self-reported stroke recovery (SIS score) and higher FIM scores at baseline were predictors of lower stress scores (p = .02 for both variables) during 12 months post discharge (Table 5). In addition, a higher mutuality scale score was a strong predictor of a lower PSS score (p < .01) indicating that stroke survivors who perceived that they had a strong positive relationship with their spousal caregiver reported less stress. Lower self-rated health status at discharge was a significant predictor of an increased stress score (p < .01).

Predictors of Perceived Stress in Spousal Caregivers

Linear mixed model analysis of caregiver PSS scores showed that higher stroke survivor function at baseline (FIM score) was a predictor of lower caregiver stress (p < .01) during the 12 months post-discharge (Table 6). Increasing caregiver age was also found to predict lower stress scores (p = .02). Female caregivers had significantly higher PSS scores than male caregivers, and lower caregiver self-rated health status at discharge was also a predictor of higher stress during the 12 months after discharge. Unlike stroke survivors, caregiver mutuality was not found to be a significant predictor of the stress score (p = .07).

Higher values on the emotional and informational support sub-scale on the MOS Social Support Scale was predictive of a decreased PSS score (p < .01). In addition, spousal caregivers who reported the availability of a greater number of people in their support network also reported a decreased PSS score during the 12 months after discharge (p < .01) Higher scores on the reframing subscale of the F-COPES instrument was found to predict lower stress scores (p = .02) while a greater use of passive appraisal coping skills was found to predict greater stress (p < .01). Total score on the Caregiver Preparedness scale was the strongest predictor of the PSS score, with higher preparedness scores predictive of lower caregiver stress (p < .01).

DISCUSSION

Stress scores reported by stroke survivors and caregivers within a dyad were correlated with each other and on average, were consistent with moderate stress. Spousal caregivers reported higher stress than stroke survivors, and over the year their stress decreased less. In the literature stress has been associated with a number of factors, the most common being stroke survivor function, [53] the relationship between the couple,[31, 36] coping,[10, 11] and social support.[14] Research has primarily reported snapshots of stress in caregivers of stroke survivors at isolated points in time. Little focus has been placed on stress experienced by stroke survivors[2] and no studies have been reported that sought to correlate the stress experienced by married stroke survivors and their spousal caregivers as they sought to adjust to living at home with a new disabling condition.

Stroke survivor function, was significantly associated with stress for both stroke survivors and spousal caregivers. Higher function in stroke survivors at discharge from inpatient rehabilitation, as measured by the FIM, significantly predicted lower stress at every time point during the year for both members of the dyad. This is consistent with other studies that have reported associations between function and strain in co-resident spousal caregivers of stroke survivors,[29] as well as associations between higher functioning and better psychological outcomes for stroke survivors.[9] Segal and Schall[53] found that caregivers' stress scores were directly related to the stroke survivors' FIM scores at six months post-stroke and that function

was also associated with stroke survivors' satisfaction with their lives. In this study stroke survivors who reported high levels of stress throughout the year were those who had poorer function, perceived that their health was poor and felt that they were making a poor recovery from the stroke at the time of discharge.

Higher stress in spousal caregivers was also predicted by poor health, in addition to being female and being younger. However, preparation for caregiving responsibilities was the strongest predictor of stress in spousal caregivers. Caregivers who had high scores on the Preparedness for Caregiving Scale experienced low levels of stress during the next 12 months. This preparedness included being able to take care of physical and emotional needs of the stroke survivor, respond to emergency situations, get information and help from the health care system and find resources and set-up services.[35]

In this study some stroke survivors were sent home with FIM scores as low as 21 and perceived recovery scores of 0 on a scale of 0–100%. This degree of impairment will predictably create high levels of stress in stroke survivors and spousal caregivers unless couples are provided with a significant amount of education, personal care assistance and social support. It is imperative that stroke survivors who are being discharged with FIM scores below 80 have caregivers who are prepared with the skills necessary to provide adequate physical and psychological care.[54] In addition, this is a target group of caregivers who are at risk for poor health outcomes due to the heavy demands of caregiving.[4] External buffers in the form of rehabilitation and home-care services, stroke support groups that focus on self-efficacy, and family social support will be necessary if these caregivers are to avoid burn-out and subsequent institutionalization of their spouses.[5]

Preparation for caregiving also needs to include stress management skills and anticipatory guidance in managing not only the physical, cognitive, and behavioral changes in the stroke survivor, but also the changing dyadic relationship, and the loss of their own life rhythm. In this study, spousal caregivers who reported that their families were able to reframe their situation had lower stress levels throughout the 12 months post-discharge period. Families who can effectively communicate with each other and with health care providers, are good at problem solving, believe that stressful events are a fact of life and that problems are best faced "head-on" report less stress[48] and play an active role in rehabilitation, treatment adherence, and reintegration of stroke survivors into the community.[15]

On the other hand, in this study, spousal caregivers who reported that their families used passive appraisal coping strategies, that is, they believed that luck played a big role in events, that no matter what they did they would have trouble solving problems, and that if they waited long enough problems would go away, reported high levels of stress throughout the 12 months. Bhogal et al[15] in their literature review concluded that there was strong evidence that active counseling and educational interventions can improve problem solving skills.[18, 55,56] Lack of knowledge and insecurity in the caregiving role and family dysfunction may combine to create a situation where stroke survivors receive less than optimal care.[57]

Researchers have reported that stress in stroke survivors and spousal caregivers is affected by the relationship within the couple. [20, 31, 36] It is interesting to note that in this study a high level of mutuality was very strongly associated ($p < .01$) with low levels of stress in stroke survivors, but did not reach a level of statistical significance ($p = .07$) in spousal caregivers. Mutuality is a measure of interconnectedness, love, appreciation and pleasure that is shared between individuals, as well as the degree to which one provides the other with comfort, help, and emotional support.[35] Purk and Richardson[57] reported that morale scores were positively correlated between stroke survivors and their spouses. Deficits related to the stroke may result in an unequal distribution of support and help within the dyadic relationship that may morale

and feelings of mutuality. Stroke survivors who are more dependent and less engaged in outside activities may view the connectedness with the spouse as very important in maintaining some control over external events, while caregiving spouses may see the relationship as part of the unpredictably and stress in their lives.

Qualitative research has shown that while stroke survivors report the stroke as an experience of "loss and effort," [58] caregivers report a transformation in the relationship that results in a greater awareness of the fragility of life with heightened vigilance, loss of aspects of the person that they knew and also loss of connections to others with a resultant feeling of responsibility for "everything."[20] Health care professionals need to increase their understanding of the experience of stroke from the perspective of both the stroke survivor and the caregiver. While they will experience stroke differently, both need to be taught as much about stroke and its trajectory as they can absorb. The dyad may need 1) help in evaluating their relationship, 2) professional assistance in dealing with issues of control and conflict, 3) support to build on the strengths of the past relationship, 4) help to find creative ways to restore the parts of the relationship that they value, and 5) strategies to involve other family member in sharing heavy new responsibilities. When caregiving is meaningful[35] and satisfaction is greater than the hassles, caregivers of stroke survivors report less stress.[59] Pierce[36] found that in an urban African American sample of caregivers of stroke survivors, caring was viewed as mutuality. This mutuality arose, not from the dyadic relationship between the couple, but from the interdependency within the family and extended community of family and friends.

The absence of social support has been associated with stress in stroke survivors and family caregivers.[14, 19, 20, 31] In this study, the availability of emotional and informational support from family and friends was associated with lower stress levels in spousal caregivers. In addition, caregivers who reported more family and friends to talk to (in actual numbers) also reported lower levels of stress during the year. Caregivers sometimes lose contact with their support network because the disabilities associated with stroke make transportation difficult, the time required to provide care leaves little energy for social interactions, or because they lose their connection to others, believing that "they don't understand."[20] Health care professionals may employ telephone and computer technology to link caregivers together regardless of distance or disability. Family caregivers who participated in a web-based support program reported that the experience of "pulling together" and feeling connected with other caregivers helped them to decrease their stress.[31]

CONCLUSION

Stress and coping theory posits that dyads experiencing a major event like a stroke may find their lives to be unpredictable, uncontrollable and overloaded and that these feelings of stress may interfere with their ability to negotiate their daily lives and reintegrate back into the community. Research in this area, however, with few exceptions, has focused primarily on family caregivers, not stroke survivors[2] and few people have used a dyadic approach in their research with stroke survivor and caregiver couples.[57] By measuring stress every three months in both members of the co-resident dyads, this study increases our understanding of the relationship of stress within the dyad, how stress levels change during the first year at home, and the similarities and differences in predictors of stress for each member of the dyad.

The significant decrease in stress during the year may suggest that couples in this study were able to use internal and external resources to help them to decrease their stress. Predictors of stress varied between stroke survivors and spousal caregivers. For the couple, perceiving that they had good health was a predictor of having lower stress levels. The only variable that was related to stress in both members of the dyad was stroke survivor function; good function was related to lower stress. The mutuality between the couple was only a significant predictor in

stroke survivors, indicating that while a positive relationship might act as a buffer to lower stress in stroke survivors, it did not reach the level of significance in spousal caregivers. Consistent with the ABCX Model of stress and coping, we found in this study that the availability of emotional and informational social support, the number of available family and friends, and the use of reframing strategies to face and solve problems were related to lower stress levels in spousal caregivers during the year after discharge from inpatient rehabilitation.

Stress has the potential to negatively impact the care provided by spouses and the stroke survivor's recovery.[34] This study helps us to identify some buffers that rehabilitation professionals need to focus on to improve long-term outcomes for stroke survivors and spousal caregivers. This includes specific attention to maximizing the stroke survivor's function before discharge home, and optimizing the variables that may help to buffer the stress that is inevitably associated with stroke after discharge home – stroke survivor impairment, dyadic relationship, caregiver health, knowledge and perception of the disease, social support, and coping strategies that foster realistic approaches to problem solving. An interdisciplinary team of rehabilitation professionals (i.e., physicians, nurses, therapists, psychologists) have an important role in maximizing recovery and minimizing stress for couples long after the inpatient phase of rehabilitation is over. Stroke is a life changing event that requires adaptation and a transformation in the rhythm of life for the couple.

Acknowledgments

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Table 1

Variables Assessed in Linear Mixed Models for Association with Stress in Stroke Survivors and Spousal Caregivers over 12 months

Model	Block Entered into Analysis	Variables
Caregiver & Stroke Survivor	Demographic & Contextual Variables	age, gender, ethnicity, days since stroke, socioeconomic status, self-rated health (single item score), stroke survivor function (total FIM score), mutuality (mutuality scale score)
Caregiver	Mediating Variables	coping strategies (F-Copes sub-scale scores), social support (MOS Support structural and functional sub-scale scores), caregiver preparedness (preparedness scale score)
Stroke Survivor	Mediating Variables	perception of recovery (Stroke Impact Scale single score on scale from 0–100)

Table 2

Stroke Survivor (SS) and Caregiver (CG) Sociodemographic Profile at Baseline

	SS (n=159)		CG (n=159)	
Variable	$\overline{X}$	**SD**	$\overline{X}$	**SD**
Age	66.4	9.1	62.5	10.5
Socioeconomic Status	43.44	11.62	43.44	11.62
	n	**%**[*]	**n**	**%**[*]
Gender				
Male	119	74.8	40	25.2
Female	40	25.2	119	74.8
Race				
Minority	67	42.1	67	42.1
Non-Hispanic White	92	57.9	92	57.9
Education				
< High School	26	16.4	24	15.1
High School Graduate	36	22.6	33	20.8
Partial College	41	25.8	50	31.5
College Graduate	56	35.2	52	32.7

[*] may sum to >100% due to rounding

Table 3

Means (SD) and Ranges for Variables Included in the Final Predictive Models for Stroke Survivors and Caregivers (n=159 couples)

	Stroke Survivor		Caregiver	
Variable	**X (SD)**	**Range**	**X (SD)**	**Range**
Mutuality (Possible range 0–4)	3.46 (0.52)	1.87–4.00	3.27 (0.66)	0.80–4.00
Self Rated Health Status (Possible range 1–5)	3.06 (1.06)	1–5	2.82 (1.03)	1–5
Stroke Survivor Function (FIM) (Possible range 18–126)	89.86(23.06)	21–124	--	--
Perception of recovery (Possible range 0–100)	52.15(23.80)	0–100	--	--
Emotional/Informational Support (Possible range 0–100)	--	--	70.30 (25.95)	0–100
Number of people available to provide support	--	--	11.40 (10.84)	1–52
F-COPES Sub-scale Reframing (Possible range 8–40)	--	--	32.37(4.71)	16.00–40.00
F-COPES Sub-scale Passive Appraisal (Possible range 4–20)	--	--	14.03(3.47)	4.00–20.00
Preparedness (Possible range 0–4)	--	--	2.81(0.72)	0.38–4.00

Table 4

Mean (SD) Change over Time on the Perceived Stress Scale (PSS) for Stroke Survivors and Caregivers

Month	Stroke Survivor		Caregiver	
	$\overline{X}$	SD	$\overline{X}$	SD
Inpatient Discharge	12.27	7.46	14.00	7.25
3 months	11.46	7.41	14.44	7.35
6 months	10.72	7.13	13.52	7.44
9 months	10.75	7.55	13.54	7.44
12 months	10.47	7.30	13.21	7.12

Table 5

Final Model Explaining Stress in Stroke Survivors

Effect	F-value	p-value
Time (Days)	19.12	< 0.01
Stroke survivor function (FIM)	5.28	0.02
Perception of recovery	5.51	0.02
Stroke survivor health	10.63	< 0.01
Mutuality	33.72	< 0.01

Table 6

Final Model Explaining Stress in Caregivers

Effect	F-value	p-value
Time (Days)	4.98	0.03
Gender	11.75	< 0.01
Age	5.94	<0.02
Stroke survivor function (FIM)	12.42	< 0.01
Caregiver health	7.17	< 0.01
Reframing coping strategy	5.21	0.02
Passive appraisal coping strategy	8.71	< 0.01
Mutuality	3.28	0.07
Emotional & informational support	14.70	< 0.01
Preparedness for caregiving	25.18	< 0.01
Number of close friends & relatives	8.40	< 0.01