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Abstract

BACKGROUND: Caregivers of stroke survivors experience high rates of mental and physical morbidity. Stroke has sudden onset, and the outcome is not immediately known. Uncertainties surrounding the new caregiving role may not only necessitate major changes in the lives of family caregivers but also contribute to negative health outcomes for the caregiver.

PURPOSE: The purposes of this study were to describe caregiver uncertainty across the early weeks after a family member's stroke and to explore characteristics of caregivers and stroke survivors associated with that uncertainty.

METHODS: A prospective, longitudinal exploratory observational study was conducted with a convenience sample of 40 caregivers and older adult (≥65 years) stroke survivors recruited from urban acute care settings in the mid-Atlantic region. Caregivers were enrolled by 2 weeks poststroke (T1) and revisited 4 weeks later (T2). Uncertainty was measured using the Mishel Uncertainty in Illness Scale for Family Members. An unadjusted linear mixed model was computed to examine significant associations between each caregiver or stroke survivor characteristic and repeated measures of uncertainty.

RESULTS: Uncertainty at T1 (83.73 ± 23.47) was higher than reported in other caregiver populations and remained high 6 weeks poststroke (T2: 85.23 ± 23.94). Each of the following characteristics was independently associated with greater caregiver uncertainty: caregivers' older age ($p = .019$), being a spouse ($p = .01$), higher stress ($p < .001$), more depressive symptoms ($p = .001$), more comorbidities ($p = .035$), and poorer coping capacity ($p = .002$) and stroke survivors' recurrent stroke ($p = .034$), poorer functional status ($p = .009$), and insurance type ($p = .008$).

CONCLUSIONS: Caregivers experienced persistently high uncertainty during the first 6 weeks poststroke. Better understanding of uncertainty, its associated characteristics, and its outcomes may help clinicians identify caregivers at highest risk who may benefit from targeted interventions.

Caregiving Immediately after Stroke: A Study of Uncertainty in Caregivers of Older Adults

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Abstract

Background—Caregivers of stroke survivors suffer high rates of mental and physical morbidity. Stroke has sudden onset and the outcome is not immediately known. Uncertainties surrounding the new caregiving role may not only necessitate major changes in the lives of family caregivers, but also contribute to negative health outcomes for the caregiver.

Purpose—The purposes of this study were to describe caregiver uncertainty across the early weeks after a family member's stroke and to explore characteristics of caregivers and stroke-survivors associated with that uncertainty.

Methods—A prospective, longitudinal exploratory observational study was conducted with a convenience sample of 40 caregivers and older adult (65 years) stroke survivors recruited from urban acute-care settings in the mid-Atlantic region. Caregivers were enrolled by 2 weeks poststroke (T1) and revisited 4 weeks later (T2). Uncertainty was measured using the Mishel Uncertainty in Illness Scale for Family Members. An unadjusted linear mixed model was computed to examine significant associations between each caregiver or stroke-survivor characteristic and repeated measures of uncertainty.

Results—Uncertainty at T1 (83.73 ± 23.47) was higher than reported in other caregiver populations and remained high 6 weeks poststroke (T2: 85.23 ± 23.94). Each of the following

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characteristics was independently associated with greater caregiver uncertainty: caregivers' older age ($p = 0.019$), being a spouse ($p = 0.01$), higher stress ($p < .001$), more depressive symptoms ($p = .001$), more comorbidities ($p = 0.035$), and poorer coping capacity ($p = 0.002$) and stroke-survivors' recurrent stroke ($p = 0.034$), poorer functional status ($p = 0.009$) and insurance type ($p = 0.008$).

Conclusions—Caregivers experienced persistently high uncertainty during the first 6 weeks poststroke. Better understanding of uncertainty, its associated characteristics, and its outcomes may help clinicians identify caregivers at highest risk who may benefit from targeted interventions.

Introduction

In the United States, approximately 66 million people serve as informal caregivers of family members or friends who are older, chronically ill or disabled (National Alliance for Caregiving and AARP, 2009), and caregiver status is a known risk factor for morbidity and mortality (Haley, Roth, Howard, & Safford, 2010; Schulz & Beach, 1999). Uncertainty, defined as "inability to determine the meaning of illness-related events" (Mishel, 1988, p. 225), may be present in the immediate period following assumption of the caregiver role. Uncertainty may contribute to untoward outcomes, yet factors associated with uncertainty are not clearly explicated. Caregivers of stroke survivors are exemplars of those whose introduction to caregiving may occur suddenly and in the face of life threatening circumstances for the care recipient; thus, early caregiving after stroke provides a unique opportunity for exploring uncertainty (Byun & Evans, 2014; White, Barrientos, & Dunn, 2014).

According to the middle-range nursing theory of uncertainty in illness, uncertainty includes four dimensions: (a) ambiguity about the illness state; (b) complexity regarding available information, treatment, the healthcare system and relationship with healthcare providers; (c) lack of information about the diagnosis, seriousness of the illness, treatment and symptoms; and (d) unpredictability of the illness course and prognosis (Mishel, 1988). Uncertainty is the cognitive state when the person is unable to structure or categorize an event because of insufficient clues (Mishel, 1997a). It arises when the decision maker cannot assign definite values to events and/or anticipate outcomes because of lack of resources or information (Mishel, 1997b). In other populations, uncertainty has been related to depression, anxiety, and perceived stress and caregiving itself has been shown to have poor health outcomes (Mitchell & Courtney, 2004; Sanders-Dewey, Mullins, & Chaney, 2001; Shannon & Lee, 2008). Caregiver characteristics and stroke-survivor characteristics (e.g., caregiver's coping capacity, social support or health, or stroke survivor's functional status) supported by previous studies on outcomes, such as burden, in caregivers of stroke survivors, may also be related to uncertainty. Caregivers' uncertainty about stroke survivors' outcomes may be heightened because of the very real difficulty, in the early poststroke period, of predicting just how much physical or cognitive impairment will remain (Byun & Evans, 2014).

Thus, understanding whether and how uncertainty may influence overall ability to provide care, especially in stroke survivor caregivers, may be important in preventing adverse health

effects in this group. Uncertainty, however, has not been well studied in stroke survivor caregivers (White et al., 2014), especially in the early weeks of caregiving. One of the few studies of uncertainty in stroke survivors and caregiving revealed that both stroke survivors and caregivers experienced uncertainty about future events, signs and symptoms of stroke, stroke risk factor management and resources available for poststroke care (White et al., 2014). Both stroke survivors and caregivers express uncertainty and worry about the possibility of recurrent strokes (Greenwood, Mackenzie, Wilson, & Cloud, 2009; White et al., 2014), which are often more severe and reflect more serious illness (Hankey, Jamrozik, Broadhurst, Forbes, & Anderson, 2002).

Older adults have a higher incidence of stroke and these stroke survivors require more assistance and care from their family members; these caregivers are often spouses who may have their own sets of illnesses. Caregivers with comorbidities may experience difficulty taking on caregiving responsibilities or resolving uncertainty by seeking new knowledge or information. Thus, a study of caregivers' responses in the early period after first or recurrent stroke in older adults is critical to understanding the role of uncertainty as a potentially modifiable factor affecting caregiver outcomes.

Revealing caregiver and stroke survivor characteristics that influence uncertainty during this period may identify caregivers at highest risk for uncertainty and suggest potential areas for intervention to prevent negative consequences from occurring later in the stroke caregiving trajectory. Thus, the purposes of this study were to describe caregiver uncertainty across the early weeks after a family member's stroke and to explore characteristics of caregivers and stroke-survivors associated with that uncertainty.

Methods

We implemented a prospective, longitudinal exploratory observational study using a convenience sample of caregivers and their stroke-survivor relatives. Caregivers were enrolled at the hospital within the first 2 weeks following their relatives' stroke (baseline: T1) and revisited 4 weeks later (~6 weeks poststroke: T2). We chose two waves of data collection to examine any change in uncertainty or its related factors over time during the early weeks of the poststroke period. In addition, by 6 weeks poststroke, stroke survivors are more likely to have been discharged (to home, rehabilitation hospitals or nursing facilities), with an expectation for caregivers to be more directly involved in their care. Caregivers and stroke survivors were recruited from acute-care settings in two Philadelphia academic health-science centers. Approval for the study was obtained from the Institutional Review Boards from both sites.

Sample

To be included in the study, caregivers had to (a) self-identify as both a family member and the expected primary caregiver for an older adult (age 65 or older) who had been diagnosed within the past 2 weeks with new or recurrent ischemic or hemorrhagic stroke, (b) communicate in English, (c) demonstrate capacity for informed consent and (d) be 21 years of age or older. We also reviewed medical records of stroke survivors following self- or surrogate-written agreement.

Procedures

A research team member trained in the study protocol visited each participating hospital unit to identify, screen and enroll eligible participants. The research team member first inspected a daily list derived from electronic medical records to identify patients admitted with stroke. Nursing leaders on the units helped identify potential caregiver participants. To confirm eligibility for enrollment, stroke survivors' paper charts and/or electronic medical records were consulted to verify age of stroke survivor and to obtain caregiver contact information. If caregivers met all of the inclusion criteria and expressed an interest in participating, written informed consent from the caregiver was obtained. Subsequently, the research team member also obtained from stroke survivors or their surrogates informed consent and Health Insurance Portability and Accountability Act of 1996 (HIPPA) authorization to access the stroke survivor's medical record. Consenting caregivers were interviewed in person in a private place at the hospital or in caregivers' homes at T1. For T2 data collection, caregivers were telephoned to arrange a meeting at a place convenient to them. Relevant health information was collected from the stroke survivors' medical records at T1, and selected items were repeated using caregiver as proxy at T2.

Study Variables and Instruments

Uncertainty—Uncertainty was measured using the 31-item Mishel Uncertainty in Illness Scale for Family Members (Mishel, 1997a). Items capture uncertainty defined as the caregiver's inability to determine the meaning of illness-related events (Mishel, 1997a). Each item is scored on a scale of 1 (*strongly disagree*) to 5 (*strongly agree*). Total sum scores range from 31 to 155; high scores indicate greater uncertainty. Internal consistency for the total scale is from 0.81 to 0.92 (Cronbach's alpha) for family caregivers (Mishel, 1997a); in our study, Cronbach's alpha was 0.92 at T1 and 0.95 at T2.

Caregiver characteristics and stroke-survivor characteristics supported by previous studies on outcomes, such as burden, in caregivers of stroke survivors were collected. With the exception of sociodemographic and clinical characteristics (in stroke survivors), all variables were measured at both time points.

Caregiver Characteristics

Socio-demographic characteristics: These included age, sex, race/ethnicity, household income, and questions about relationships and preparedness. Participants were asked to rate their household income as: 1) comfortable, have more than enough to make ends meet; 2) adequate, have enough to make ends meet; or 3) do not have enough to make ends meet. Perceived quality of relationship with the stroke survivor (on a scale of 1 = *excellent* to 4 = *poor*) and perceived level of preparedness for caregiving (on a scale of 1 = *Well prepared* to 4 = *not at all prepared*) were also obtained.

Stress: Perceived stress was measured by the Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983), which includes 14 items designed to assess symptoms of stress and global measures of the degree of stress experienced in "the last month, including today." In our study, the time parameter was modified to ask about stress experienced "in the past day" (24 hours) because at T1, "the last month" would have preceded the relative's stroke. Each

item was scored from 0 (*never*) to 4 (*very often*) with total sum scores ranging from 0 to 56; higher scores indicated higher perceived stress. Cronbach's alpha of the scale ranges from 0.84 to 0.86 (Cohen et al., 1983). Cronbach's alpha in our study was 0.86 at T1 and 0.88 at T2.

Depressive symptoms: The Patient Health Questionnaire (PHQ-9) is a 9-item scale used as a diagnostic screening measure for major and minor depression (Kroenke & Spitzer, 2002). This scale assesses the frequency of symptoms such as disinterest, low mood, sleep disruption or tiredness over the last 2 weeks, and each item is scored from 0 (Not at all) to 3 (Nearly every day). Total score ranges between 0 and 27 and severity of depression can be described as none (score 1 to 4), mild (5 to 9), moderate (10 to 14), moderately severe (15 to 19) and severe (20 to 27; Kroenke & Spitzer, 2002). Cronbach's alpha was 0.86 at T1 and 0.89 at T2.

Comorbidity: A modified version of the Cumulative Illness Rating Scale (CIRS; Miller et al., 1992) was used to measure caregivers' comorbidity, that is, the presence of coexisting chronic diseases. Total scores (Miller et al., 1992) range from 0 (*no impairment*) to 56 (*maximal impairment*) across 14 systems. Scoring of each system followed the guidelines proposed by Hudon, Fortin, and Vanasse (2005). The CIRS is a valid and reliable measure of multi-morbidity (Hudon et al., 2005).

Coping capacity: A 13-item short-form version of the Sense of Coherence tool (Antonovsky, 1987) was used to measure how well caregivers coped with stress associated with caregiving. Sense of coherence refers to "one's ability to respond to stressors by the appropriate use of adaptive coping resources" (Chumbler, Rittman, Van Puymbroeck, Vogel, & Qin, 2004, p.944). Each item is scored from 1 (*never*) to 7 (*very often*), with total scores ranging from 13 to 91 where higher scores indicate greater coping capacity. Cronbach's alpha was 0.81 at T1 and 0.83 at T2.

Social support: Social support was measured using the Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet, & Farley, 1988). The scale includes 12 items designed to assess perceptions about support from family, friends and a significant other. Responses range from 1 (*very strongly disagree*) to 7 (*very strongly agree*) and higher scores indicate better levels of perceived social support. Cronbach's alpha reliability scores were 0.94 at each time point.

Stroke-Survivor Characteristics

Socio-Demographic and Clinical Characteristics: At T1, socio-demographic characteristics were collected. At T2, location or facility (e.g., rehabilitation hospital) to which the stroke survivor was transferred following T1 data collection and also the site of current placement were identified. Other clinical characteristics at T1 included severity of stroke (the NIH Stroke Scale, Cronbach's alpha: 0.87), description of stroke (type, area, presence of communication disability, days poststroke). As with caregivers, the CRIS at T1 was used to measure comorbidity in stroke survivors.

Functional status: Caregiver perception of the survivor's ability to perform activities of daily living was measured using the Barthel Index (Mahoney & Barthel, 1965). The scale has 10 items, each scored from 0 to 15. Total scores range from 0 to 100 where higher scores indicate independence from any help. In our study, Cronbach's alpha was 0.94 at both T1 and T2.

Statistical Analysis

Data were analyzed using SPSS 21.0 for Windows and Stata 13. Descriptive statistics were used to report uncertainty, stress, depressive symptoms, socio-demographic and stroke-related data (mean, standard deviation, and frequencies). Paired *t*-tests (for continuous variables) and McNemar tests (for categorical variables) were used to explore any changes over time in study variables measured at both time points. Given the large number of variables available, limited sample size and exploratory design, a separate unadjusted linear mixed model was computed to examine the relationship between each caregiver or stroke-survivor characteristic and repeated measures of uncertainty without adjustment for other variables; full maximum likelihood with random intercept at level 2 was used. Each independent variable was either time-varying (values for variables measured at both time points, e.g., coping capacity) or fixed (values for variables measured only at baseline, e.g., gender). Each model included one independent variable (e.g., age or coping capacity) and time variable (time points, T1 and T2) to determine which caregiver or stroke-survivor characteristic was independently associated with uncertainty. For all analyses, a p-value of less than 0.05 in a two-sided test was considered statistically significant.

Results

A total of 63 caregivers and stroke survivors agreed to participate in the study and were enrolled. By T2, however, 13 stroke survivors had died and their caregivers were omitted from this analysis; additionally, three caregivers withdrew from the study and seven more were lost to follow up, despite multiple attempts to contact them. Thus, 40 caregivers with data for both T1 and T2 were included. The medical records of their 40 stroke survivor relatives were reviewed. There were no missing data in this analysis. Comparing baseline characteristics of participants who completed the study ($N = 40$) and those not included in the data analysis ($N = 23$), there were no significant differences at T1 for caregiver or stroke-survivor characteristics with these exceptions: non-completers had more social support at baseline ($p = 0.036$) and they and their stroke survivors were more likely to be non-Hispanic Whites ($p = 0.018$ for caregivers, $p = 0.009$ for stroke survivors). Supplementary Table 1 summarizes caregiver and stroke-survivor sociodemographic and stroke-related characteristics. Most caregivers were female and non-Hispanic White or African American. Their average age was 58 years (± 14.22) and slightly over one third was 65 or older. Among caregivers, 37.5% had prior experience in providing post-stroke or other illness-related care to their stroke survivor relatives.

Over half of stroke survivors were female. Ages ranged from 65 to 95 years (75.6 ± 7.8). Following T1 data collection, the majority (60%) had been discharged from the acute-care hospital to a rehabilitation hospital (vs. 22.5% discharged to home, 10% to a nursing facility

and 7.5% to another place or remained hospitalized). By the time of the T2 interview, however, still only 17 (42.5%) stroke survivors were at home (vs. 27.5% at a rehabilitation hospital, 12.5% at a nursing facility and 17.5% at another place or remained hospitalized).

Table 1 summarizes the descriptive analysis and comparison of study variables measured at both time points. Compared to T1, caregivers at T2 had higher comorbidity scores, better perceived coping capacity, and less social support. Functional status of the stroke survivors improved from T1 to T2.

Characteristics Associated with Uncertainty

Each unadjusted linear mixed model that examined the association between a caregiver or stroke-survivor characteristic and repeated measures of uncertainty is presented in Table 2. Only models with significant associations are reported. In separate models, each of the following characteristics was independently associated with caregiver greater uncertainty across the first 6 weeks poststroke: caregiver's older age, being a spouse (vs. non-spouse), higher stress, more depressive symptoms, more comorbidities and poorer coping-capacity and stroke survivor's recurrent stroke, poorer functional status and insurance type (Private/ Medicare/Medicare + Supplemental Health Insurance Plan vs. Medicare + Medicaid/ Medicaid/No Insurance). Time (T1 and T2), however, was not associated with repeated measures of uncertainty in any model. In other words, uncertainty did not change by 6 weeks poststroke.

Discussion

The major finding in our study was that caregivers experienced high levels of uncertainty at baseline that were essentially unabated four weeks later. In addition to caregiver age and relationship to the stroke survivor, caregiver uncertainty was associated with stress, depressive symptoms, comorbidity and coping capacity as well as stroke survivor's recurrent stroke, functional status and insurance type.

Caregiver uncertainty was higher than had been reported in other caregiver populations (Mishel, 1997a; Mitchell & Courtney, 2004). When patients with various conditions (including cardiac, neurological, vascular and trauma) were transferred from intensive care (Mitchell & Courtney, 2004), average family members' uncertainty levels ranged from 76.2 to 78.9 vs. from 83.7 ± 23.5 to 85.2 ± 23.9 found in our study. Our findings indicate assuredly that caregivers are uncertain regarding the meaning of an illness-related event. i.e., stroke, in their family members.

In our study, caregiver perceived stress was closely related to uncertainty. The association between uncertainty (about HIV serostatus) and perceived stress has been reported (Shannon & Lee, 2008). Caregiver perceived stress was also higher than that of other population (Schwarz & Dunphy, 2003) and stress levels were consistent across 6 weeks poststroke.

While our study's caregivers, on average, reported mild levels of depressive symptoms, approximately 30% of all caregivers had moderate, moderate-to-severe or severe depressive symptoms—a rate nearly twice that reported by Bakas, Kroenke, Plue, Perkins, and

Williams (2006). The finding of a significant effect of uncertainty on depressive symptoms was reported in caregivers for persons with Parkinson's disease (Sanders-Dewey et al., 2001).

Caregivers with better coping capacity experienced less uncertainty during the first 6 weeks poststroke and they coped slightly better by 6 weeks poststroke. When individuals confront stressful life events, they use strategies to cope and adapt to the situation, thus, decreasing harmful effects that may arise from stress and/or reducing the emotionally distressing response to the event (Visser-Meily et al., 2009). Caregivers who try to cope with the situation may resolve uncertainty by seeking knowledge or information or by adopting health-promoting behavior (Mishel, 1997b).

Other caregiver characteristics related to greater uncertainty included older age, being a spouse (vs. non-spouse) and having a greater number of comorbidities. We included only caregivers of older adults with stroke. Spousal caregivers (37.5% of sample) were older than non-spousal (e.g., adult child) caregivers and 30% of all caregivers were themselves over age 65, making them at higher risk for new comorbidities. Compared to baseline, however, all caregivers reported more comorbidities at 6 weeks poststroke which is concerning. Caregiver status is closely related to caregivers' physical and psychological health (Haley et al., 2010). Family caregivers' uncertainty around a relative's transfer from intensive care was significantly related to anxiety (Mitchell & Courtney, 2004). Thus, attention to the well-being of this group, especially older spousal caregivers, is important.

Despite previous caregiving experience, our sample of caregivers of stroke survivors with a recurrent stroke experienced higher uncertainty scores (97.67 ± 24.22 at baseline and 97.78 ± 24.37 at 6 weeks poststroke) than did those caring for survivors with a first stroke (79.68 ± 22.01 at baseline, 81.58 ± 22.93 at 6 weeks poststroke). A recurrent stroke predicts stroke survivor institutionalization, disability, and death (Hankey et al., 2002). In our study, these caregivers may have felt greater uncertainty due to discouragement related to fear of severe disability, declining function or slower recovery or increased possibility of death of their relatives.

Poorer functional status of stroke survivors was associated with greater uncertainty in our sample. Although others have reported no association with caregiver burden (Morimoto et al., 2003), our results are consistent with those who reported that stroke survivors' functional status is associated with caregiver outcomes such as stress (Ostwald, Bernal, Cron, & Godwin, 2009). Our findings support existing recommendations for aggressive rehabilitation in stroke patients.

Stroke survivors' insurance type was associated with caregiver uncertainty. Caregivers of stroke survivors with either private insurance, Medicare or Medicare plus supplemental health insurance may have felt greater uncertainty due to the diverse care options available to the stroke survivors, more requirements to make choices and decisions, a complex billing process or ambiguity regarding coverage of medical expenses. Alternately, those with such resources may be more used to taking personal control in situations; an inability to control

the medical situation may accentuate caregivers' feelings of uncertainty, but further investigation is needed to understand this finding.

Implications for Clinical Practice

Timely recognition of and attention to uncertainty and its associated factors as well as the development and testing a targeted intervention for uncertainty may help family members better cope in their role as informal caregivers. Using early detection of uncertainty as a trigger to initiate caregiver interventions may decrease perceived stress as well as uncertainty and reduce morbidity and mortality in caregivers. Healthcare providers must become sensitive to caregiver expressions of uncertainty and help them identify specific areas where they are uncertain (e.g., the recovery process, caregiver role). For example, items in the Mishel Uncertainty in Illness Scale for Family Members, such as, "I don't know what is wrong with him/her" or "I am unsure if his/her illness is getting better or worse" (Mishel, 1997b), suggest specific areas for tailored interventions. In our study caregivers reported less social support at 6 weeks poststroke compared to baseline. Social support (including instrumental and informational as well as emotional and companionship support) is an important buffer known to decrease stress in stroke survivors and their caregivers (Ostwald et al., 2009). Our findings underscore the importance of helping caregivers identify and access sources of support. Strategies applied to stroke or other caregiving groups may be applicable to caregivers of stroke survivors. For example, applying a 'coping by finding meaning in caregiving' strategy similar to that of Chumbler, Rittman and Wu (2008) may help decrease uncertainty and depressive symptoms. Similarly, promoting coping capacity to initiate caregiver action, such as seeking consultation or engaging in behavioral interventions as suggested by Mishel (1997b) may lead to decreased uncertainty. Other adaptive strategies such as establishing routines, keeping a sense of humor and identifying positives may be helpful in managing uncertainty in caregivers of stroke survivors (Greenwood et al., 2009).

Limitations and Strengths

Limitations of this study include convenience sampling from a single geographic region. Due to the relatively small sample size, we were unable to control caregiver or stroke-survivor characteristics in a single linear mixed model. As an initial step, it was important to describe early uncertainty in this population and to explore caregiver and stroke-survivor characteristics related to it. Given the large number of variables analyzed in this study, however, a type I error is possible. We also included caregivers of patients with either first or recurrent stroke, which could have introduced additional heterogeneity into the sample. Further studies with a larger sample are required to clarify whether significant differences exist between caregivers of survivors with a first or recurrent stroke. Finally, attrition was 38%, higher than desired but not surprising considering the timing of data collection.

Strengths include a longitudinal design and the diversity of the sample with respect to caregiver gender and race/ethnicity. The prevalence of stroke is higher in African Americans and approximately 66% of lay caregivers in the United States are women (National Alliance for Caregiving and AARP, 2009). Although race/ethnicity and gender did not influence uncertainty in our study, further research with a larger number of African American and male caregivers may reveal racial/ethnic and sex differences in uncertainty.

Conclusions

Uncertainty does not abate rapidly in caregivers following stroke, especially caregivers who are older, spouses, stressed or depressed, and those with their own illnesses, poor coping capacity, or those caring for survivors with a recurrent stroke or poor functional status. These characteristics may help clinicians to identify caregivers at risk for uncertainty early in the caregiving period and most in need of supportive interventions to help prevent untoward effects. Our findings support the need for research on the long-term consequences of uncertainty on caregiving and the testing of interventions to resolve or ameliorate the negative effects of uncertainty with the ultimate goal of enhancing caregiver outcomes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements

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Table 1

Comparison of Study Variables between T1 and T2 (*N*=40)

Variable [Range]	*M ± SD or N(%)* at T1	*M ± SD or N (%)* at T2	*t* statistic	*p* value
Caregiver Characteristics				
Duration of Caregiving (days)	4.63 ± 3.75	36.03 ± 6.96		
Time Spent Caring per Day (hours)	8.7 ± 6.29	7.60 ± 6.59	0.954	0.346
Perceived quality of relationship with the stroke survivor (from 1 = excellent to 4 = poor)	1.28 ± 0.64	1.50 ± 0.75	−1.940	0.060
Perceived level of preparedness for caregiving (from 1 = excellent to 4 = poor)	2.15 ± 0.98	2.25 ± 1.01	−0.561	0.578
Stress[†] [0-56]	24.38 ± 10.15	24.47 ± 10.74	−0.080	0.936
Depressive Symptoms[†] [0-27]	7.25 ± 5.84	6.60 ± 5.96	0.891	0.379
Comorbidity[†] [0-56]	5.65 ± 4.37	6.20 ± 4.69	−2.054	0.047
Coping Capacity[†] [13-91]	63.85 ± 12.52	67.25 ± 15.46	−2.061	0.046
Social Support[†] [7-84]	71.15 ± 13.14	63.88 ± 18.18	2.560	0.014
Other Life Event	17 (43%)	9 (23%)		0.057
Stroke-Survivor Characteristic				
Functional Status[†] [0-100]	26.25 ± 28.83	43.75 ± 36.56	−3.266	0.002
Main Caregiver Variable				
Uncertainty[†] [31-155]	83.73 ± 23.47	85.23 ± 23.94	−0.713	0.480

Note. M = mean; *SD* = standard deviation. Paired *t*-test was used for all variables except other life event for which McNemar test was calculated.

[†] Higher scores = higher stress, more depressive symptoms, more comorbidities, better coping capacity, better social support, better functional status, or greater uncertainty.

Table 2

Each Caregiver and Stroke-Survivor Characteristic Associated with Uncertainty based on Unadjusted Linear Mixed Models (*N* = 40)

Predictors	B	SE	z statistic	p value	95% CI
Caregiver Characteristics					
Model 1					
Age	0.55	0.24	2.34	0.019	[0.09, 1.02]
Time	1.5	2.08	0.72	0.470	[−2.57, 5.57]
Model 2					
Child/Sibling			Reference		
Spouse	17.59	6.79	2.59	0.01	[4.28, 30.90]
Time	1.5	2.08	0.72	0.47	[−2.57, 5.57]
Model 3					
Comorbidity	1.38	0.65	2.11	0.035	[0.10, 2.66]
Time	0.74	2.10	0.35	0.724	[−3.38, 4.87]
Model 4					
Coping Capacity	−0.49	0.16	−3.12	0.002	[−0.80, −0.18]
Time	3.18	2.25	1.42	0.157	[−1.22, 7.58]
Model 5					
Stress	1.01	0.19	5.45	< 0.001	[0.65. 1.38]
Time	1.40	1.79	0.78	0.434	[−2.01, 4.99]
Model 6					
Depressive Symptoms	1.21	0.36	3.38	0.001	[0.51, 1.92]
Time	2.29	2.08	1.10	0.272	[−1.80, 6.37]
Stroke-Survivor Characteristics					
Model 7					
Insurance Type					
Private/Medicare/Medicare+Supplemental			Reference		
Medicare+Medicaid//Medicaid/No Insurance	−22.83	8.62	−2.65	0.008	[−39.73, −5.92]
Time	1.5	2.08	0.72	0.47	[−2.57, 5.57]
Model 8					
First Stroke			Reference		
Second Stroke	17.09	8.07	2.12	0.034	[1.28, 32.9]
Time	1.5	2.07	0.72	0.47	[−2.57, 5.57]

Predictors	B	*SE*	*z* statistic	*p* value	95% CI
Model 9					
Functional Status	−0.14	0.05	−2.60	0.009	[−0.25, −0.03]
Time	3.96	2.23	1.77	0.076	[−0.41, 8.33]

Note. B = unstandardized slope coefficient; SE = standard error; CI = confidence interval.