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Predictors of Life Satisfaction in Stroke Survivors and Spousal Caregivers Twelve to Twenty-Four Months Post Discharge From Inpatient Rehabilitation

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Abstract

A global measure of life satisfaction has become increasingly important as an adjunctive outcome of health care interventions for individuals with disabilities, such as those caused by a stroke. Furthermore, life satisfaction of the stroke survivor may also impact the caregiving spouse. The purpose of this study was to determine, among many physical and psychosocial variables, those that were associated with life satisfaction in the couple at 12 months after discharge from inpatient rehabilitation, and those that were predictive of life satisfaction one-year later (24 months). Between 12 and 24 months life satisfaction decreased for stroke survivors while it increased for caregiving spouses. The relationship between the couple (mutuality) was the only variable that was a significant predictor of life satisfaction for both stroke survivors and their spouses.

Keywords

Stroke; cardiovascular accident (CVA); life satisfaction; stroke survivor; caregiver; spouse; relationship

Almost 6 million stroke survivors are alive today in the United States; most of them live at home with family (American Heart Association, 2008). Increases in survivorship are often accompanied by physical, psychosocial, affective, and cognitive disabilities that affect life satisfaction of persons with stroke and their family, especially their spouses. A 2006 National Stroke Association survey of long-term stroke survivors found that 87% had ongoing motor problems, 54% had trouble walking, 52% had trouble with hand movements, and 58% experienced spasticity (Jones, 2006). These continuing disabilities significantly decrease their life satisfaction, and also the life satisfaction of their spouses.

Because of new rehabilitation techniques and a change in our understanding of brain plasticity, nurses will care for stroke survivors receiving therapy, not only immediately after their stroke,

but on subsequent hospitalizations for months and even years after the initial event. Thus a fuller understanding of the factors that influence a couple's life satisfaction after stroke is important. The purpose of this paper is to report the predictors of life satisfaction in stroke survivors and their spousal caregivers between 12 and 24 months after discharge from inpatient rehabilitation.

Literature Review

Considerable literature exists about the meaning of terms such as life satisfaction, well-being, and quality of life (QOL). (A fuller discussion of this literature can be found in Ostwald, 2008). General agreement exists that QOL is a complex, multi-dimensional concept that includes both objective and subjective elements (Lau & McKenna, 2001; Low, Payne & Roderick, 1999). In this paper, life satisfaction is defined as a global measure of quality of life that represents a general subjective appraisal of one's life and does not necessarily mean satisfaction with all aspects of life (Campbell, 1981; Diener, 1984; Musschenga, 1997). An individual's subjective appraisal of life may be different from objective appraisals made by others (Veenhoven, 2000). Life satisfaction can only be understood from the individual's perspective (Campbell, 1981). While life satisfaction is generally considered to be stable (Schimmack, Diener & Oishi, 2002), changes in health, relationships, and work have been shown to significantly decrease life satisfaction (Lucas, Clark, Gerogellis & Diener, 2003).

A recent narrative review found most studies to report lower life satisfaction in stroke survivors and their spousal caregivers than in the general population (Ostwald, 2008). However, variations in instruments, settings, and time in recovery have lead to inconsistent conclusions. Only a few studies have followed stroke survivors for greater than 12 months, and even fewer have looked at life satisfaction in their caregiving spouses. In general, decreased life satisfaction in stroke survivors has most often been reported to be related to motor impairments, limitations in daily activities, and persistent aphasia (Bays, 2001), and post-stroke depression (King, 1996). Viitanen and colleagues (1988) reported that 61% of stroke survivors were still dissatisfied with their lives 4–6 years after their strokes. Long-term stroke survivors (> 5 years) report stagnation in recovery of functioning, which is associated with decreased life satisfaction (Teasdale & Engberg, 2005).

Depression and poor life satisfaction in stroke survivors have been shown to be positively related to depression and burden in caregivers (Anderson, Linto & Stewart-Wynne, 1995). Decreased spousal life satisfaction has been shown to be associated with the stroke survivor's physical and cognitive impairments (Forsberg-Warleby, Moller & Blomstrand, 2004), and the couple's lack of reintegration into normal patterns of living (White, Poissant, Cote-LeBlanc & Wood-Dauphinee, 2006). Only 50% of spousal caregivers were satisfied with their lives "as a whole" one year after the stroke (Visser-Meily, Post, Schepers & Lindeman, 2005). Spouses experienced more strain, worry, and disruption in their daily lives than adult children caregivers. For at least one year post-stroke, spouses of stroke survivors are at greater risk for poorer health, restricted social contacts, and poorer life satisfaction (Franzen-Dahlin, Larson, Murray, Wredling & Billing, 2007).

In the chronic disease literature, the relationship between caregiver and care-receiver (Archbold, Stewart, Greenlick, & Harvath, 1990), the meaningfulness and manageability of caregiving (Haley, LaMonde, Han, Burton, & Schonwetter, 2003), and family functioning (Palmer & Glass, 2003) have been associated with life satisfaction. Spouses of stroke survivors who had cognitive and emotional impairments were the most likely to be dissatisfied with their relationship (Forsberg-Warleby, et al., 2004). In a study of stroke survivors and spouses at 12 months post stroke, Carlsson and colleagues (2007) reported that satisfaction with life as a whole, and the domains of leisure and sexual functioning were most affected for both stroke

survivors and spouses after a stroke. Relationship with the partner was the only domain in which stroke survivors reported greater satisfaction than their spouses.

Methods

Study Design and Sample Population

The sample for this study was 131 stroke survivors and their spousal caregivers who completed 12-months of the CARES (Committed to Assisting with Recovery after Stroke) study (NR005316). CARES was a prospective longitudinal intervention study that randomized stroke survivors and their spousal caregivers into either a mild or intensive intervention upon discharge from inpatient rehabilitation. (For more information about the intervention, see Ostwald, Davis, Hersch, Kelley & Godwin, 2008).

CARES participants had to have been a cohabitating, English-speaking couple with one member hospitalized with a diagnosis of stroke. The stroke survivor had to be at least 50 years of age, without global aphasia, with no additional major physical or psychiatric conditions (i.e. severe Parkinson's disease, dementia) and not on hospice. The sample was recruited between November, 2001 and December, 2005 from five hospitals within the Texas Medical Center, a large medical complex located in Houston, Texas. They were followed for 24 months. (For more information on the recruitment and retention of the CARES sample, see Schulz, Wasserman & Ostwald, 2006). CARES was approved by the university Institutional Review Board (IRB) and by the IRB committees of the hospitals from which patients were recruited.

Data Collection

A trained research nurse collected data from stroke survivors and spousal caregivers in their homes twelve months after discharge from inpatient rehabilitation. Caregivers completed the paper and pencil instruments while data were gathered from stroke survivors by interview. Data on life satisfaction were collected by telephone from stroke survivors and their spouses at 18 and 24 months post discharge. All data were collected using standardized instruments which have been previously shown to be valid and reliable. Socio-demographic data (age, gender, race/ethnicity, occupation, and educational level) were collected and the four-factor Hollingshead scale was used to calculate socio-economic status (SES) based on the couple's occupation and educational level (Hollingshead, 1979).

Instruments

The variables shown in Table 1 have been demonstrated in previous studies to be related to life satisfaction in patients with chronic illnesses (Anderson, et al., 1995; Archbold, et al., 1990; Bays, 2001; Forsberg-Warley, et al., 2004; Haley, et al., 2003; King, 1996). Only instruments measuring variables shown to be significant predictors of life satisfaction for stroke survivors or their spouses in the final models (Table 3 and Table 4) are discussed below.

The Satisfaction with Life Scale (SWLS) is a 5-item scale measuring global life satisfaction and has been shown to have high internal consistency and temporal reliability (Diener, Emmons, Larsen & Griffen, 1985). Participants respond on a 7-point scale with "1" being "strongly disagree" and "7" being "strongly agree". All items are summed to give a total score. Higher scores indicate greater satisfaction.

The Self-Rated Health Status is a one-question subjective measure of an individual's perceived health status; it has been shown to be a valid health status indicator (Idler & Benyamini, 1997; Miilunpalo, Vuori, Oja, Pasanen & Urponen, 1997). Participants respond to the question, "In general, would you say your health is:" on a 5-point scale (1 -excellent, to 5-poor). Lower scores indicate better perceived health status.

Mutuality, a 15-item scale assessing the strength of the relationship between the caregiver and the care-receiver, is measured on a 4-point scale (Archbold et al., 1990). The total mutuality scores range from 1 to 4 after averaging the responses to the 15 items. High scores indicate the relationship between caregiver and care-receiver is characterized by love, shared pleasurable activities, common values, and reciprocity. High internal consistency has been reported with Cronbach's alpha ranging from .91 to .95 (Archbold et al., 1990; Carter, Stewart, Archbold, Inoue, Jaglin, & Lannon, 1998).

The Perceived Stress Scale (PSS) (Cohen & Wills, 1985) is a widely used instrument for measuring the degree to which participants perceived life to be stressful (i.e., unpredictable, uncontrollable, and overloading), during the past month (Gallagher-Thompson; Brooks, Bliwise, Leader, & Yesavage, 1992; Gottlieb, Golanter, Bar-Tal, & Gottlieb, 2001; Fredman, Daly, 1997; Keir, Guill, Carter, Boole, Gonzales, & Friedman, 2006; McCallum, Sorocco, & Fritsch, 2006). Participants make their ratings on a 5-point scale (0-never to 4-very often) with total scores ranging from 0 to 40. The scale has high internal consistency (.78) and has demonstrated moderate correlations with other measures of appraised stress.

The Geriatric Depression Scale (GDS-15) is a brief scale designed to assess depression in older adults (Sheikh & Yesavage, 1986). Items are summed for a total score; the scale has a cut-off of 4/5 for significant depressive symptomatology. The GDS-15 has a high level of internal consistency (Cronbach's alpha = 0.80), and all of the individual items are significantly associated ($p < 0.01$) with the total score (D'Ath, Katona, Mullan, Evans & Katona, 1994).

The Stroke Impact Scale (SIS), version 2, is a stroke-specific quality of life instrument measuring the physical, mental and emotional impact of stroke (Duncan et al., 1999). The SIS includes 59 questions in eight domains: strength, hand function, mobility, activities of daily living, emotion, memory, communication and social participation. Higher scores indicate a higher quality of life. The first four domains can be combined into the SIS Physical domain score. The 1-week test-retest reliability correlation coefficients for the 8 SIS domains ranged from .70 to .92 with the exception of the emotion domain which was .57 (Duncan et al., 1999). However, Cronbach's alpha for the SIS emotion domain in the CARES study was .81.

Caregiver Preparedness is an 8-item scale measuring general, physical, social, and emotional preparedness for caregiving. Participants answer questions on a 5-point Likert scale (0-not at all prepared to 4-very well prepared). The responses to the 8 items are averaged with the scores ranging from 1 to 4. Higher scores indicate greater caregiver preparedness (Archbold et al., 1990).

Data Analysis

Longitudinal analyses of Satisfaction with Life Scale (SWLS) scores from 12 to 24 months were conducted with linear mixed models (Brown & Prescott, 2006). Separate models were developed for the stroke survivors and their spousal caregivers. A sequential method (Tabachnick & Fidell, 2001) was used to determine from the list of variables presented in Table 1 those factors that are significant predictors of life satisfaction. For the stroke survivor model, demographic and other 12-month contextual variables were entered as a block to comprise the initial model. A second model was constructed by adding 12-month instrument scores for the SIS. Significant variables resulting from this second model were tested for their interaction with time (in days) to determine if their association with life satisfaction changed between 12 and 24 months. A similar process was used for the caregiver model with demographic and other 12 month contextual variables being entered as a block to comprise the initial model. A second model was constructed by adding 12 month instrument scores for coping, social support, and preparedness to those variables that were found to be significant predictors ($p < .05$) of life satisfaction in the first model. The procedure for determining the final model for spousal

caregiver life satisfaction was the same, except in the second model the 12 month PSS values were centered to their mean value (13.2). To improve interpretability of the models, the values for time were centered to the midpoint of follow-up (179.5 days). The final model included only those variables and interactions with a p value $< .05$. All statistical analyses were performed using SAS for Windows, version 9.1 (SAS Institute, 2004).

Results

Profile of Participants

Seventy-seven percent of the stroke survivors were male in this sample. As can be seen in Table 2, considerable diversity existed in terms of age, ethnicity and SES. While the average age of spouses was 63, the ages ranged from 41 to 86 years. Forty-two percent of the sample was minorities with almost equal numbers being African American and Hispanic, representative of the Houston area. In addition, participants came from a wide range of socioeconomic backgrounds, with a range on the SES scale of 13 to 66 and a mean of 43.5.

Life Satisfaction Changes Over Time

Mean scores on the Satisfaction with Life Scale (SWLS) show changes in the opposite direction for stroke survivors and their spouses (see Figure 1). The life satisfaction scores of stroke survivors decreased from a mean of 23.79 (SD=6.62) at 12 months to a mean of 22.42 (SD=6.73) at 24 months, demonstrating a significant decrease over the 12-month follow-up. However, life satisfaction scores for the caregivers showed a trend in the opposite direction with an increase in satisfaction from 24.25 (SD=6.73) at 12 months to 25.16 (SD=5.94) at 24 months. The difference in scores between the spouses widened from being almost identical (0.46 points difference) at 12 months to being almost 3 points different (2.74 points) at 24 months.

Predictors of Life Satisfaction in Stroke Survivors

Linear mixed model analysis of the 12 to 24 month stroke survivor scores on the SWLS can be seen in Table 3. A significant decrease in life satisfaction occurred from 12 to 24 months ($p = .04$). The presence of depression at 12 months was a strong predictor of decreased life satisfaction. However, being older, having high scores on the mutuality scale and perceiving that one was recovering emotionally from the stroke (higher SIS emotion sub-scores) were all predictors of higher life satisfaction between 12 and 24 months post inpatient rehabilitation. None of these associations with stroke survivor life satisfaction were found to change significantly over time.

Predictors of Life Satisfaction in Spousal Caregivers

Linear mixed model analysis of 12 to 24 month caregiver SWLS scores showed an improvement in caregiver life satisfaction over time (slope estimate for time of .002 per day). However, this increase was not found to be statistically significant. Caregivers who perceived that their health was poorer (higher scores on the Self-rated Health Status Scale) and perceived greater stress (PSS score) at 12 months demonstrated decreased life satisfaction from 12 to 24 months. The negative association of PSS score with life satisfaction was found to change significantly over time ($p = .01$), with the estimate of the slope (.0005) indicating that this association became less negative over time. Increased caregiver life satisfaction was associated with increased 12 month Mutuality and Preparedness scores. Those who had a good relationship with their spouse and felt prepared for the caregiving role reported higher life satisfaction.

Discussion

A global measure of quality of life (QOL) has become increasingly important as an adjunctive outcome of health care interventions. Satisfaction with health care and resultant satisfaction with life with a disability or chronic disease have become issues of interest to clinicians and researchers.

Scores on the SWLS in this sample of stroke survivors at 12 months were only slightly below the norms for older community dwelling individuals (24.25) (Pavot, Diener, Colvin, & Sandvik, 1991). While some studies of long-term stroke survivors have found relatively high rates of life satisfaction (Lindmark & Hamrin, 1995), most studies have shown that life satisfaction norms are below those of the general population (Ostwald, 2008). The lack of large differences in this study is consistent with Campbell's (1981) assertion that most individuals seek to maximize their sense of well-being and to perceive their life as positively as possible. Using a technique referred to as a "standard gamble," Hallan and colleagues (1999) concluded that most stroke survivors did not view stroke as an overwhelming catastrophe.

This study, however, found that between 12 and 24 months, life satisfaction scores declined in the stroke survivors. Post-stroke depression at 12 months was a strong predictor of poor life satisfaction over the ensuing year. This is consistent with other studies that have found a strong relationship between post-stroke depression and life satisfaction up to three years post-stroke (Bays, 2001; Lofgren, Gustafson & Nyberg, 1999). Physical function was not a significant predictor of life satisfaction in this study, as has been reported in other studies. However, the survivors may have experienced stagnation in their physical recovery leading to depression and decreased life satisfaction, as was reported by Teasdale and Engberg (2005) in their 5–15 year follow-up. Being older was associated with a higher level of life satisfaction. Others have reported that younger survivors may have additional social issues, including work and child-care, that may negatively affect their life satisfaction (Teasell, McRae, & Finestone, 2000). Rehabilitation nurses need to be alert for signs of continuing post-stroke depression and advocate for pharmacological, psychological, and social therapies that may help to relieve the depression and thus increase life satisfaction.

Spousal caregivers' mean on the SWLS was identical at 12 months (24.25) to the older community-dwelling population mean, and actually surpassed the population mean at 24 months. This is contrary to other studies that have reported significantly lower life satisfaction among caregivers at 12 months, as compared to the general population (Forsberg-Warleby, et al, 2004). For caregivers, their own health, a perception of their preparedness for the caregiving role, and the stress associated with daily life were significantly related to life satisfaction. This suggests that preparation for the caregiving role is not a one-time event that occurs at the time of the stroke. Over time the needs of the stroke survivor change, both physically and emotionally, and the health status of the caregiver may decline. Nurses encountering spousal caregivers need to continue to assess the caregiver's current knowledge, skills, and resources, and provide appropriate learning opportunities and referrals. This education may focus on the caregiver's own health needs, needs of the stroke survivor, and/or stress management techniques and community resources.

The only variable that was a significant predictor of life satisfaction for both stroke survivors and spousal caregivers was their relationship. Couples who expressed a high degree of mutuality (e.g., love, enjoyment of each other) were most satisfied with their lives. This predictor did not change over time and was as strong at 24 months as it was at 12 months. Strokes occur within the context of an existing relationship, which may or may not be mutually rewarding. While nurses cannot change a long-term marital relationship, they do need to be aware of the stresses that a stroke can place on any relationship. Research has demonstrated

that physical and cognitive impairments, dysfunctional families, lack of ability to communicate, and/or lack of ability to function socially or sexually, may interfere with a couple's relationship, interfere with adjustment to the stroke, and interfere with life satisfaction (Clark & Smith, 1999; Eriksson, Tham & Fugl-Meyer, 2005; Forsberg-Warleby, et al, 2004; Korpelainen, Nieminen & Myllyla, 1999). Rehabilitation nurses need to assist couples to anticipate and cope with changes that the stroke will make in many areas of their lives. While the rehabilitation team focuses on physical, cognitive, occupational, and speech therapy, the nurse must also help the couple to access their strengths and challenges in terms of family support, marital relationship, coping strategies, spiritual resources, lifestyle priorities, and financial and environmental challenges. Working with couples to increase their life satisfaction long term will require making realistic plans to meet short and long-term challenges. Kautz (2007) provides excellent suggestions for how rehabilitation nurses can intervene to effectively enhance intimacy among couples. Interventions to improve relationships often require an interdisciplinary effort that may include social workers, psychologists, clergy, and peer counselors, as well as referrals to community agencies and support groups.

This study has two major limitations. First, the couples' satisfaction with life and the quality of their marital relationship were not known prior to the stroke so it is not possible to know how much impact the stroke itself had on either life satisfaction or mutuality scores. Second, since life satisfaction was not measured until 12 months post discharge, it is not known whether life satisfaction changed in a positive or negative direction during the first 12 months post-discharge. However, other studies that have looked at life satisfaction during the first 12 months have reported a negative impact of the stroke on the life satisfaction of the stroke survivor and also the caregiving spouse.

This study has implications for rehabilitation nurses who are concerned about helping stroke survivors and their caregiving spouses to experience long-term life satisfaction. Assessing stroke survivors for post-stroke depression on every encounter and providing continuing treatment may be an important strategy for increasing life satisfaction since depression is a significant predictor of poor life satisfaction. Stroke survivors who perceived that they were doing well emotionally at 12 months had higher levels of life satisfaction at 24 months, a further confirmation of the need to treat depression. Spousal caregivers who had good health, felt confident about their caregiving ability, and who reported less stress at 12 months had higher life satisfaction at 24 months. Nurses have an important role in teaching and affirming spouses in their caregiving roles and encouraging them to care for their own health. Finally rehabilitation nurses need to be alert to the impact of the stroke on the relationship between the couple and to assist them in identifying challenges and developing realistic plans to minimize the negative effects of the stroke, and in strengthening their relationship as they face life after a stroke together.

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Figure 1. Mean Satisfaction With Life Scale (SWLS) Scores Over Time For The stroke Survivors and Spousal Caregivers. (Vertical bars represent the standard error of the mean for a group at that time point.)

Table 1

Variables Assessed in Linear Mixed Models for Association with Life Satisfaction (SWLS)

Model	Block	Variables
Caregiver	12 Month Demographic & Contextual Variables	age, gender, ethnicity, socioeconomic status, caregiver self-rated health, stroke survivor function, caregiver depression, caregiver perceived stress, caregiver burden, caregiver mutuality
	12 Month Mediating Variables	coping strategies, social support, caregiver preparedness
Stroke Survivor	12 Month Demographic & Contextual Variables	age, gender, ethnicity, socioeconomic status, stroke survivor self-rated health, stroke survivor function, stroke survivor depression, stroke survivor perceived stress, stroke survivor mutuality
	12 Month Mediating Variables	overall perceived recovery, perceived physical ability, perceived emotional ability, perceived memory ability, perceived communication ability, perceived social participation

Table 2

Sociodemographic and Stroke-Related Characteristics of Stroke Survivors and Their Spousal Caregivers at 12-Months Post Discharge from Inpatient Rehabilitation (n=131)

Stroke Survivors				Caregivers			
Variable	N	%	Variable	N	%		
Male	101	77.1	Male	30	22.9		
African American	23	17.6	African American	22	16.8		
Asian	5	3.8	Asian	5	3.8		
Non-Hispanic White	76	58.0	Non-Hispanic White	77	58.8		
Hispanic	22	16.8	Hispanic	23	17.6		
Other	5	3.8	Other	4	3.1		
	$\bar{X}$	SD	Range	$\bar{X}$	SD	Range	
Age	66.9	9.1	51.1–88.6	Age	63.0	10.6	
SES	43.5	12.0	13.0–66.0	SES	43.5	12.0	
Health Status	2.61	0.89	1.0–5.0	Health Status	2.9	1.0	
Depression	3.2	2.7	0–15.0	Depression	2.88	2.86	
Stress	10.5	7.3	0–30.0	Stress	13.2	7.2	
Mutuality	3.3	0.7	1.3–4.0	Mutuality	3.0	0.8	
SIS Physical	69.1	23.1	6.0–100.0	Preparedness	2.9	0.7	
SIS Emotion	80.9	16.2	11.0–100.0				
SIS Memory	85.0	16.2	11.0–100.0				
SIS Communication	88.3	18.6	11.0–100.0				
SIS Social Participation	72.7	21.1	0–100.0				

Table 3

Predictors of Stroke Survivor Satisfaction With Life Scores 12–24 Months After Discharge from Inpatient Rehabilitation

Variable	Estimate	DF	F	P Value
Time (Days)	−.004	1, 89.9	4.43	.04
12 Month Age (Years)	.09	1, 117	4.98	.03
12 Month Geriatric Depression Scale	−.52	1, 123	7.61	.01
12 Month Mutuality Score	1.71	1, 114	8.22	.01
12 Month Stroke Impact - Emotion Subscale	.11	1, 118	15.16	< .01

Table 4

Predictors of Caregiver Satisfaction With Life Scores 12–24 Months After Discharge from Inpatient Rehabilitation

Variable	Estimate	DF	F P	P Value
Time (Days)	.002	1, 98.6	1.74	.19
12 Month Self-Rated Health Status	−1.13	1, 117	9.27	< .01
12 Month Perceived Stress Scale	−.27	1, 115	20.46	< .01
12 Month Mutuality Score	2.49	1, 112	22.62	< .01
12 Month Preparedness Scale	1.23	1, 127	4.48	.04
Time * 12 Month Perceived Stress Scale	.0005	1, 97.9	6.24	.01