

Predictors of life satisfaction among stroke survivors and spousal caregivers: a narrative review

Sharon K Ostwald

The University of Texas
School of Nursing at Houston,
6901 Bertner Avenue,
SONSCC – Room 644,
Houston, TX 77030, USA
Tel.: +1 713 500 9940;
Fax: +1 713 500 0266;
E-mail: sharon.k.ostwald@
uth.tmc.edu

Stroke is a major cause of disability and death worldwide. It affects 15 million people globally and 60% either die or are permanently disabled as a result of stroke. In a rapidly aging population, stroke is expected to continue to be a major concern for survivors, their families and health and social care providers. Most stroke survivors live in the community and are assisted by family caregivers, especially spouses. However, stroke-related impairments and poststroke depression interfere with recovery and result in impaired relationships and reduced life satisfaction for the survivors and their spouses. New interventions are needed to assist stroke survivors and their spouses to cope with the many physical, emotional and environmental changes that result after stroke and enable survivors to become reintegrated into the community.

Impact of stroke on survivors & spousal caregivers

Stroke is a major cause of mortality and morbidity throughout the world. There are approximately 700,000 new and recurrent strokes in the USA each year and 15 million worldwide [201]. Globally, almost 6 million people die from stroke each year, many in developing countries [201]. Worldwide, even in countries with advanced technology, 60% of persons who experience a stroke die or become permanently disabled, needing the assistance of others [201]. Stroke is the leading cause of long-term disability among older adults in the USA [202] and in Great Britain [201]. Approximately 5.8 million stroke survivors are alive today in the USA at an annual cost to Americans of US\$62.7 billion in 2007 [202]. In 2000 in Great Britain, 4% of the NHS spending was on stroke services [201]. Stroke survivors often experience devastating physical, psychosocial, affective and cognitive disabilities that affect their satisfaction with life. 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 [203]. The burden of stroke is referred to by economists as disability-adjusted life years (DALYs). DALY combines the years of potential life lost to premature death from stroke with the years of productive life lost to disability from stroke. The global stroke burden is projected to increase from 38 million DALYs in 1990 to 61 million DALYs in 2020 [201].

Most stroke survivors return home after the initial hospitalization and are assisted in the recovery process by a primary family caregiver, usually the spouse. The full impact of the stroke and its sequelae may not be fully realized until several months posthospital discharge. Physical, psychological, emotional and cognitive changes associated with stroke impact the family as well as the stroke survivor. In several studies, spouses of stroke survivors perceived most caregiving burden in terms of feelings of loss, heavy responsibility, uncertainty about the survivors' daily care needs, difficulty managing safety and behavioral problems, constant worries, restraints in social life and feelings that survivors relied only on their care [1–4]. These changes affect the health and life satisfaction of spousal caregivers. This paper reviews the concept of life satisfaction and provides a narrative overview of the literature related to life satisfaction in stroke survivors and spousal caregivers.

Methodology

The following four databases were searched for 1960 to February, 2008: OVID (PsychINFO) Medline(R), EBSCO Medline, PubMed (NLM) and SCOPUS. The following search terms were used in several combinations: satisfaction with life, life satisfaction, quality of life (QOL), wellbeing, sense of wellbeing, happiness and stroke, cerebral vascular accident (CVA), stroke survivor, caregiver, spouse and spousal caregiver. Extensive searching occurred using the references from published articles obtained from the computerized searches. Articles were only included if they were in English, or if the article was a review of literature with an abstract or summary in English.

Keywords: adaptation, caregivers, cerebrovascular disease, depression, family function, life satisfaction, quality of life, spouses, stroke survivors, wellbeing

future medicine part of fsg

For the analysis of the concept of life satisfaction, articles were chosen to represent a broad range of opinions on life satisfaction, wellbeing and QOL. In addition, references were given to as many instruments that purported to measure these concepts as could be identified. Articles were included if they discussed older adults and/or adults with chronic illnesses and disabilities. For the remainder of the narrative review, articles were included in the discussion if they:

- Included stroke survivors and spousal caregivers in their samples;
- Included an overall measure of life satisfaction whether the authors referred to it as life satisfaction, satisfaction with life, overall QOL or overall wellbeing.

Concept of life satisfaction

Lack of clarity exists in the literature regarding the definition of terms, such as wellbeing, life satisfaction, happiness and QOL [5,6]. In 1984, Diener concluded from a review of the literature stretching back to 1967, that the term 'subjective wellbeing' included the concept of life satisfaction [7]. Early work on subjective wellbeing identified two components, an affective component (pleasant or unpleasant affect) and a cognitive or judgmental component (life satisfaction) [8]. While some studies have used the terms health status, functioning, QOL and wellbeing interchangeably with life satisfaction [9], most scholars believe that these terms are not synonymous in meaning [10].

Life satisfaction is often referred to as global QOL [6,11]. The term wellbeing has been preferred in the social sciences, while the term QOL has been more heavily used in medical sciences [5]. QOL has become increasingly valued as an adjunctive outcome of healthcare interventions. General agreement exists that QOL is a complex, multidimensional concept that includes both objective and subjective elements [10,12]. Veenhoven points out, however, that the subjective and objective appraisals may not be in agreement [6]. Four components have been suggested as major contributors to QOL in stroke survivors:

- Physical health, including disease and treatment-related symptoms;
- Functional health represented by mobility, self care and role performance;

- Psychological health, which includes wellbeing, emotional status, satisfaction with life and happiness;
- Social health represented by the amount and quality of social networks [10].

These four components are also major contributors to QOL in caregivers. It is the diverse multidimensional aspects of QOL that Musschenga calls the 'container concept'. He argues for conceptual clarity and the use of discrete terms, such as life satisfaction for global subjective wellbeing and other discrete terms for physical, psychological and social functioning [5].

Life satisfaction represents a general subjective appraisal of one's life and does not necessarily mean satisfaction with all aspects of life [5,13]. Many instruments have been used to measure life satisfaction, QOL and wellbeing in stroke survivors and their family caregivers [14–22]. How they differ conceptually is not always clear. A number of comparisons and evaluations of instruments commonly used with stroke survivors and their family caregivers have been published to address this issue [23–27].

The concept of life satisfaction has been shown to be discriminable from positive and negative effects and from optimism and self-esteem [28]. The feeling of wellbeing is a personal experience that can only be understood from the individual's perspective [13]. Individuals use their own criteria to determine satisfaction with their lives. The domains of self, standard of living, family life, marriage, friends and work are believed to have greater influence on general life satisfaction than environmental domains (housing, neighborhood, community and nation) [13]. However, the causal direction has not been established and some argue that general life satisfaction affects the specific domains, rather than specific domains influencing the general appraisal of life satisfaction [28,29]. The domains of wellbeing are not weighted equally and vary among individuals. In addition, the relative value of each domain is influenced by the individual's developmental phase of life and culture [30]. While life satisfaction has been shown to be a relatively global and stable concept [31,32], events such as a negative change in health, relationships or work can have a strong influence over long-term levels of life satisfaction [33]. Campbell pointed out that a change in life satisfaction could result from a perceived change in circumstances and/or a change in aspirations [13]. This change might

reflect a real change or a change in the psychological perspective from which the individual views the situation. Veenhoven used the term adaptation to describe situations when the objective circumstances of life are negative, but the persons' appraisal of life is positive [6]. Researchers who used a technique referred to as a 'standard gamble' with stroke and nonstroke medical patients concluded that most people did not view stroke as an overwhelming catastrophe [34]. Most individuals seek to maximize their sense of wellbeing and to perceive their life as positively as possible [13].

Life satisfaction & disability *Impact on stroke survivors*

In general, healthy older people tend to report as much satisfaction with life as younger people. Campbell attributed this to the narrowing of discrepancies between aspirations and achievements in older ages. As people age, their achievements increase and their aspirations tend to fall [13]. However, health problems may increase this discrepancy and, thus, lead to less life satisfaction for those in poorer health. People with disabilities are most likely to express dissatisfaction with their lives; dissatisfaction with health translates into dissatisfaction with life [13]. Satisfaction with oneself, feeling physically attractive and perceiving control over one's life may all affect a person's perceived satisfaction with life. Individuals who experience a disabling disease, such as a stroke, experience a change in many of the attributes associated with being satisfied with self. While some studies, especially studies of long-term stroke survivors, have found relatively high rates of life satisfaction [35], most studies have demonstrated that stroke survivors and their caregivers report life satisfaction lower than matched samples in the general population. Clarke and colleagues found in their national study of Canadian seniors with strokes, that functional disabilities in instrumental activities of daily living (e.g., cooking and doing laundry) were associated with a reduced sense of mastery and control, reduced opportunities for personal growth and reduced ability to engage in positive social relationships [36]. Self-efficacy and self-esteem have also been shown to correlate with life satisfaction [11,37,38]. The type and location of the stroke may also impact the stroke survivor's perception of wellbeing [39,40]. De Haan and colleagues found only weak associations with side of the stroke, but survivors with

supratentorial strokes reported poorer function at 6 months poststroke than those with infratentorial strokes [39]. Using MRIs to pinpoint lesions, however, Moon and colleagues reported that severe subcortical lesions were associated with lower overall QOL [37].

Motor impairments, limitations in daily activities and aphasia that persist over time have a negative effect on life satisfaction [41–43]. Activity level has been found to be a significant predictor of life satisfaction in stroke survivors [42,44–46]. Returning to work was a major factor in predicting positive life satisfaction for younger stroke survivors [47–51]. Reports about stroke survivors' ability to return to work poststroke vary with estimates from 9.4% in younger stroke survivors 3 months poststroke [50] to 62% in stroke survivors with aphasia 2 years after discharge [51]. In order to return to work, some survivors required changes assignments or working hours or found different employment [46]. Younger survivors with higher educational levels who have white-collar jobs were more likely to return to work, but findings vary based on the measures used and the follow-up periods [52].

In general, stroke survivors reported less satisfaction with life than the general population [53]. Some researchers have reported a decline in specific domains of QOL from 3 to 12 months after discharge [54–56], while others have shown an improvement in the mean overall QOL score between 4 and 16 months after stroke [38,57,58]. An increase in global QOL in spite of decreased physical function suggests some internal adaptation to changes in the life situation [57]. In a longitudinal study of stroke survivors, coping strategies were shown to be a powerful determinant of life satisfaction 9–12 months after discharge [59], and religious beliefs have been shown to influence the coping ability and, thus, increase life satisfaction [60]. Recent studies have shown that female stroke survivors experienced less functional recoveries and had lower QOL summary scores than males [61]. Even stroke survivors who were mildly physically disabled were less satisfied with their lives than controls in the general population [45]. Viitanen and colleagues reported that 61% of stroke survivors were still dissatisfied with their lives 4–6 years after their strokes [41]. In their 5-, 10- and 15-year follow-ups of stroke survivors, Teasdale and Engberg concluded that symptoms, functioning and social conditions tended to become stagnant in

long-term survivors [62]. As a group, stroke survivors were less satisfied than their spouses on most domains of life satisfaction [63].

Impact on spousal caregivers

Spouses of stroke survivors also reported significantly lower life satisfaction than the general population [53,64], although in most domains, caregivers scored higher than the stroke survivors [57]. Only 50% of spousal caregivers were satisfied with their lives ‘as a whole’ 1 year after the stroke [65]. Factors that contributed to lower life satisfaction were apprehensiveness about increased responsibility and new tasks related to caregiving, and fewer opportunities to pursue their own interests [66,67]. Changes in life satisfaction that occurred by 4 months poststroke continued to persist and were generally more marked at 12 months [68]. Decreased spousal life satisfaction has been shown to be associated with the stroke survivors’ physical and cognitive impairments [53,68–70], and the lack of reintegration into normal patterns of living [71]. In addition, spouses’ satisfaction with their own daily activities, leisure and self-care were associated with stroke survivors’ physical impairment and low self-care ability. However, spousal caregivers’ ability to cope with the burden and strain of the caregiving situation, not the stroke survivors’ activities of daily living dependency, was the strongest predictor of life satisfaction in the study by Visser-Meily and colleagues [65].

Life satisfaction & depression

Poststroke depression

Poststroke depression (PSD) is a very common and complex phenomenon with potential interactions among anatomical and psychosocial factors [72,73]. PSD has repeatedly been shown to be associated with stroke survivors’ wellbeing and to potentially jeopardize the recovery process [35,74]. Stroke-related impairments (physical, cognitive and speech) and depression have repeatedly been shown to predict lower life satisfaction among stroke survivors [42,75–81]. In one study 3 years after stroke, depression still had a very strong association with wellbeing [82]. Depression and poor life satisfaction in stroke survivors have also been shown to be positively related to depression and burden in caregivers [83–86].

Depression in spousal caregivers

Caregivers of stroke survivors experienced high levels of depression [65,83,84,87], which persisted for at least 12 months poststroke [65,86], with

their self-estimated general wellbeing and their own health status being the major predictors [88]. Spousal caregivers often reported feeling a loss of control over their lives, a loss of social interactions and increasingly poorer health. Recent research has suggested gender differences with female spouses reporting more depression and lower overall wellbeing than male spouses [89]. Spousal caregivers have reported poorer health and lower levels of wellbeing than adult children caregivers [90]. Studies continue to demonstrate that caring for a stroke survivor has a negative impact on spousal caregivers’ wellbeing, resulting in not only a high level of depression, but also a high level of strain [87,91]. Spouses experiencing severe strain and worry have also been shown to have as much as a 63% higher chance of dying within the next 4 years than the general population [92]. The higher levels of burden in spouses are primarily related to their emotional distress and their perception of the survivor’s ability, and less to the amount of care they provided or to survivors’ characteristics [87,91]. A meta-analysis of 60 studies of wellbeing among informal caregivers reported that uplifts of caregiving were associated with subjective wellbeing and caregiving stressors were associated with depression [69]. Caregiver depression was best predicted by lower life satisfaction, lower physical functioning and a lack of tangible social support [93].

Life satisfaction & finding meaning

Finding meaning in the event has previously been shown to be a positive predictor of adjustment after a stroke for survivors and caregivers [94]. Caregivers who perceived caregiving as less stressful and more meaningful experienced less depression and higher life satisfaction [94]. Archbold *et al.* reported that caregivers who had positive relationships with their care receivers experienced less strain because they found caregiving inherently meaningful [95]. Antonovsky postulated that a sense of coherence, a global orientation to life that includes ‘meaningfulness’, ‘comprehensibility’ and ‘manageability’, mediates between stressful life events, wellbeing and health [96]. Forsberg-Warleby and colleagues tested this concept with spouses of stroke survivors, and demonstrated significant associations between sense of coherence and satisfaction with life as a whole [67]. Haley and colleagues used a stress process model to examine predictors of spousal caregivers’ depression and life satisfaction [97]. They also concluded that those who viewed caregiving as less stressful (more manageable) and

more meaningful, and remained active in social roles, experienced less depression and higher life satisfaction [97]. Finding meaning and developing a strong sense of coherence has been demonstrated to reduce distress and have a positive effect on adjustment and life satisfaction for both stroke survivors and spousal caregivers [94,98].

Life satisfaction & interpersonal relationships

In the USA, people report 'having a happy marriage' and 'having good health' as the two most important attributes of a 'good life' [13]. A happy marriage and a network of relatives and friends are important to how people evaluate their lives. Marital transitions, especially estrangements and divorces, have been associated with long-lasting changes in life satisfaction [33]. Family functioning and the relationship between the caregiver and carereceiver have been shown to be important factors in adjustment to chronic illness [99]. Relationship with the partner was the only domain in which stroke survivors reported more satisfaction than their spouses [63]. Several studies of stroke survivors and/or their spouses have reported that the stroke survivors' impairments negatively affected the relationship between the partners, family life and sexual life [41,68,100]. PSD and lack of social support have also been shown to impact the quality of sexual life and to constitute a risk factor for marital dissatisfaction [100,101]. Similarly, Carlsson and colleagues found that satisfaction with life as a whole, and the domains of leisure and sexual functioning, were most affected for both survivors and spouses after a stroke [63]. Spouses of stroke survivors who had cognitive and emotional impairments were more likely to be dissatisfied with the partner relationship, while spouses of survivors with depression and/or physical impairments were less satisfied with their sexual life [68]. Satisfaction with life and marital satisfaction contributed significantly toward explaining attitudes toward spousal caregiving for older women [102].

Stroke survivors and spousal caregivers reported negative longitudinal changes in family functioning in problem solving, family communication, role definition, behavior control and affective involvement over a 12-month period [103]. Younger survivors may have additional social issues, including work and childcare, which may affect their life satisfaction [50]. Married couples' joint perception of life satisfaction was related to their ability to function in everyday life, including participation in leisure activities and their

social life [104]. The presence of social support, the use of positive coping skills and the presence of strong religious beliefs have been associated with increased life satisfaction [59,60,105,106]. Only a third of the couples reported that they were satisfied with their life 1–5 years after the stroke [104]. Thus, family functioning, marital satisfaction, the support of family and friends, and coping ability appear to affect the adjustment process for the stroke survivors and spousal caregivers, and ultimately their satisfaction with life.

Conclusion

Life satisfaction is an increasingly important adjunctive outcome for intervention studies aimed at facilitating maximal recovery for stroke survivors living in the community and for reducing strain and burden of family caregivers, especially spouses. However, the term is used imprecisely and a myriad of generic and stroke-specific measures are used to measure life satisfaction, making comparisons among studies difficult. There is general agreement that life satisfaction is a subjective component of well-being that can be affected by developmental stage of life, culture, individual preferences, social support, family relationships and health. Life satisfaction varies within and between individuals and couples so it is difficult to generalize the findings. However, studies across many Western cultures (e.g., Australia, Canada, The Netherlands, Norway, Spain, Sweden, UK and USA) have reached similar conclusions.

The majority of studies on life satisfaction have been conducted with stroke survivors, using different inclusion criteria and different instruments. In general, stroke survivors reported reduced life satisfaction. Two predictors (impaired functioning and depression) were associated with impaired relationships with spouses; all were strong predictors of decreased life satisfaction. Stroke is a chronic disease with improvement stagnating and life satisfaction not returning to prestroke levels as many as 15 years after the stroke.

Few intervention studies are reported in the literature directed toward improving the life satisfaction of stroke survivors. However, the findings suggest that intensive rehabilitation initially and 'booster' sessions over the long term, may help to avoid decreases in function that have been observed after initial gains. Exercise programs have been shown to increase QOL and hold considerable promise as long-term interventions for stroke survivors [107].

Support and encouragement of family, friends and health professionals to practice self-care and engage in activities (leisure and work) may also increase stroke survivors' sense of self-efficacy, self-esteem and control over their lives, thus leading to less depression and greater life satisfaction [44,77]. The use of self-efficacy enhancement strategies may be helpful in achieving positive changes in self-care and activities [108]. PSD is a devastating problem that needs to be identified early and addressed through pharmacological and psychological therapies that include attention to goal setting, family relationships and the use of accommodative coping skills, which have been suggested as helpful in increasing life satisfaction for stroke survivors [42,59,109].

Relatively few studies have addressed the life satisfaction of family members caring for stroke survivors. The studies that exist include different inclusion criteria, use different instruments and cover different periods of time, making comparisons difficult [110]. However, some general themes have emerged from the literature. Functional impairments and PSD are associated with strain, burden and depression in spousal caregivers, resulting in lower life satisfaction. Spouses experienced more strain, worry and disruption in their daily lives than adult children caregivers, and are at greater risk for poorer health themselves, restricted social contacts and poorer life satisfaction for at least 1 year poststroke [88]. Spouses' perceptions of the caregiving situation, especially its manageability and meaningfulness, were as important predictors of life satisfaction as stroke survivors' impairments and depression. Social support from others, ability to continue involvement in social activities and the use of adaptive coping strategies were also associated with positive life satisfaction [97].

Caregiving literature suggests that spouses need to be included early as a part of the rehabilitation process, so that they understand the deficits caused by the stroke and institute appropriate approaches at home [111,112]. Discharge home can be an overwhelming time for spouses as they adapt to new physical, emotional and environmental demands for care. Interventions targeted to the caregivers' needs that include information, assistance with problem solving and other coping strategies, emotional support, building social networks and referral to community resources are most useful in increasing life satisfaction and can be provided in person, by telephone or over the

internet [105,113,114]. Cognitive behavioral therapy groups for spouses of stroke survivors have also proven successful in making caregiving more manageable and meaningful and, thereby, increasing life satisfaction [115]. The time devoted to caregiving often leaves spouses with little extra time to pursue health promotion and disease prevention behaviors. This is especially difficult if these activities require leaving their spouse alone, which generates fear and guilt in many caregivers [4]. Sorensen and colleagues, after their review of 71 caregiver intervention studies for disabled elders, concluded that since caregiving spouses are older, have poorer health, report more caregiving strain, have lower incomes and smaller social networks, they may need interventions that focus on their health, building supportive social networks and accessing low-cost community resources [116]. A literature review of the impact of stroke on informal caregivers [12] and a meta-analysis of interventions for informal stroke caregivers [117] both concluded that while there are a relatively small number of well-designed studies, educational and support interventions hold promise for improving life satisfaction for caregivers.

Finally, only a handful of studies have considered life satisfaction in the stroke survivor and spousal caregiver as a couple. Couples reported significant strain in the relationship, including decreased family functioning, communication, marital and sexual satisfaction, 1 year after the stroke [53,57,63,98,100,103]. Life satisfaction was higher in couples who found meaning in the experience, who used adaptive coping strategies, who had a stronger sense of coherence and those who were able to resume a resemblance of everyday normalcy though resumption of leisure and social activities as a couple. However, the small number of studies, the use of different inclusion criteria and instruments, variation within couples and varying intervals since the stroke make generalizations impossible. No intervention studies focusing on the couple, as a unit, were reported in the literature.

Future perspective

The population of people in the USA aged 65 years and older, is expected to increase from 36.8 million in 2005 to over 55 million by 2020 [204]. In 2002, approximately 37% of older persons reported severe disabilities and 16% reported that they needed assistance as a result. Stroke is a major cause of long-term disability in the USA and the incidence increases

with age. The American Heart Association estimates that the incidence of stroke doubles with every decade of life after 55 years of age [202]. While the mortality rate for stroke has declined during the last 20 years, the age-adjusted hospitalization rates increased 18.6% between 1988 and 1997 [118]. This suggests that continuing decline in stroke mortality may be due, in large part, to improved survival after acute stroke [118,119]. The increased survival of stroke survivors, combined with the continuing decrease in the average length of acute and rehabilitation hospital stays, places a significant burden on family caregivers to provide home-based care after a stroke. The vast majority of care for disabled elderly is provided by informal caregivers who number more than 22.4 million [120]. Caregivers who are over the age of 65 years are most likely to be caring for a spouse [120]. Approximately 80% of persons who live with a disabled spouse provide care to them [121]. The availability of a family caregiver is often the determining factor in whether or not persons with a stroke can be discharged to their own homes or will be placed in a nursing home. Of the elderly who need assistance with activities of daily living, but have no available family caregiver, 50% are in nursing homes, compared with only 7% who have a family caregiver [204].

Research in the next 5–10 years should focus on the careful design of randomized control trials with adequate sample sizes to test interventions that build on smaller studies with strategies shown to increase life satisfaction among stroke survivors and their spousal caregivers. Researchers should study the effect of the intervention on both stroke survivors and the caregivers since the stroke affects them individually, as well as jointly. Interventions will need to be individualized to the needs of the couple; some studies have suggested that factors predict life satisfaction differentially in stroke survivors and spousal caregivers. Research with persons with dementia and their caregivers has demonstrated that multi-component interventions are more effective than single educational or support interventions alone [122]. In addition, the effect of health service interventions on life satisfaction needs to be studied. Technology is quickly becoming available that will allow expansion and adaptation of interventions using the internet and, thus, eliminate barriers due to physical impairments, transportation needs or geographical location.

Very few studies report racial or ethnic differences in life satisfaction among stroke survivors and/or spousal caregivers. Only recently have studies begun to suggest gender differences in life satisfaction between stroke survivors and spousal caregivers. More attention is needed in both of these areas, as well as to differences related to socioeconomic status and availability of healthcare services. Multisite intervention studies that will include couples of different ethnic, racial and socioeconomic backgrounds from different geographical regions are also required in the future.

Finally, there is a proliferation of different global and domain specific instruments that have been used in life satisfaction research with stroke survivors and spousal caregivers. Both generic and stroke specific instruments are used, some focusing on life satisfaction as a global measure of QOL and some focusing primarily on specific QOL domains. Authors' theoretical basis for the choice of an instrument is usually not clear, nor is a rationale provided for the value of using one instrument as opposed to another. Several reviews of selected instruments have been published. Although none is exhaustive, general recommendations are to use stroke-specific measures with multiple domains that also include an overall global measure of life satisfaction.

Clearly, there will be an increasing need in the future to accommodate stroke survivors within our communities. Most of them will be assisted by family caregivers, often a spouse, who is also in need of special considerations from the larger community. Families who are impacted by stroke face significant physical, emotional, financial and time costs that challenge their ability to maintain a life that is mutually sustainable and satisfying. Developing multicomponent, individualized, accessible and effective interventions that are acceptable to couples and flexible enough to meet their changing needs is a challenge for researchers in the next decade.

Financial & competing interests disclosure

The author has no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.

No writing assistance was utilized in the production of this manuscript.

Executive summary

Impact of stroke on survivors & spousal caregivers

- Stroke is the major cause of long-term disability in the USA with 5.8 million survivors living in the community.
- Stroke survivors are often left with physical, psychosocial, cognitive and affective disabilities requiring assistance from family members.
- Spouses often experience significant strain, burden, poorer health and restricted social networks when they become caregivers.

Concept of life satisfaction

- Life satisfaction is a cognitive appraisal of one's global quality of life.
- Life satisfaction represents a general subjective appraisal of one's life and does not necessarily mean satisfaction with all aspects of life.
- Lack of clarity exists in the use and measurement of concepts, including life satisfaction, quality of life, wellbeing and functioning.

Life satisfaction & disability

- Impact on stroke survivors:
 - Stroke survivors report lower levels of life satisfaction than their spouses and lower levels than the general population.
 - Motor impairments, poststroke depression, limitations in daily living, aphasia and lack of leisure and work activities are major predictors of low life satisfaction.
 - Persistent low levels of life satisfaction are associated with a reduced sense of mastery and control (self-efficacy), reduced self-esteem, reduced opportunities for personal growth and reduced ability to engage in positive social relationships.
- Impact on spousal caregivers:
 - Spouses report lower levels of life satisfaction than noncaregivers and the lower levels persist over time.
 - Low life satisfaction is associated with the stroke survivor's physical, cognitive and speech impairments and lack of reintegration into the community.
 - Ability to cope with the burden and strain of the caregiving situation is the strongest predictor of life satisfaction among spousal caregivers.

Life satisfaction & depression

- Poststroke depression:
 - Poststroke depression is a common and poorly understood phenomenon with potential interactions among anatomical and psychosocial factors.
 - Poststroke depression is one of the strongest predictors of low life satisfaction.
 - Depression and poor life satisfaction in stroke survivors have been shown to be positively related to depression and burden in caregivers.
- Depression in spousal caregivers:
 - Depression in spousal caregivers is associated with poor physical health, a lack of social support and lower life satisfaction.
 - Women report more depression and lower life satisfaction related to caring for a stroke survivor than men.
 - The higher levels of burden in spouses are primarily related to their emotional distress and their perception of the survivor's ability, and less to the amount of care they provide or to survivors' characteristics.

Life satisfaction & finding meaning

- Spouses who perceived caregiving as more manageable (less stressful) and meaningful reported higher satisfaction with life.
- Finding meaning in the event and having a strong sense of coherence is associated with more positive adjustment and higher life satisfaction for stroke survivors and spousal caregivers.

Life satisfaction & interpersonal relationships

- Stroke survivors' impairments and depression negatively affected the relationship between the partners, family life and life satisfaction.
- Couples reported negative longitudinal changes in family functioning, problem solving, family communication and marital and sexual satisfaction.
- Couples joint perception of life satisfaction was related to their ability to function in everyday life, including participation in leisure and social activities.

Executive summary

Conclusion

- Life satisfaction is an increasingly important adjunctive outcome for intervention studies aimed at facilitating recovery for stroke survivors and reducing burden of spousal caregivers.
- It is difficult to generalize findings from studies of life satisfaction because they use different inclusion criteria and different instruments; few are longitudinal; and very few include the perspectives of both the stroke survivor and spouse.
- While there is general agreement that stroke survivors and their spousal caregivers experience low life satisfaction, very few randomized control trials have been reported to test interventions.

Future perspective

- Since stroke is most common after the age of 55 years, a rapidly expanding elderly population will mean an increasing number of strokes worldwide.
- More effective acute-care treatment of stroke patients means that more will survive to be discharged home with family caregivers.
- Rigorously designed randomized control trials are needed to test promising interventions to increase long-term life satisfaction among stroke survivors and spousal caregivers.
- Future research needs to investigate potential differences in life satisfaction related to gender, age, ethnicity, race, socioeconomic status, geographical location and access to affordable healthcare services.

Bibliography

Papers of special note have been highlighted as either of interest (•) or of considerable interest (••) to readers.

1. Grant JS, Glandon GL, Elliott TR, Giger JN, Weaver M: Caregiving problems and feelings experienced by family caregivers of stroke survivors the first month after discharge. *Int. J. Rehabil. Res.* 27(2), 105–111 (2004).
2. Denman A: Determining the needs of spouses caring for aphasic partners. *Disabil. Rehabil.* 20, 411–423 (1998).
3. Bakas T, Austin JK, Jessup SL, Williams LS, Oberst MT: Time and difficulty of tasks provided by family caregivers of stroke survivors. *J. Neurosci. Nurs.* 36, 95–106 (2004).
4. Coombs UE: Spousal caregiving for stroke survivors. *J. Neurosci. Nurs.* 39(2), 112–119 (2007).
5. Musschenga AW: The relation between concepts of quality-of-life, health and happiness. *J. Med. Philos.* 22(1), 11–28 (1997).
- **Philosophical discussion and analysis of commonly used terms related to life satisfaction and quality of life (QOL).**
6. Veenhoven R: The four qualities of life. *J. Happiness Stud.* 1(1), 1–39 (2000).
7. Diener E: Subjective well-being. *Psychol. Bull.* 95(3), 542–575 (1984).
8. Diener E, Emmons RA: The independence of positive and negative affect. *J. Pers. Soc. Psychol.* 47(5), 1105–1117 (1984).
9. Post MW, de Witte LP, Schrijvers AJ: Quality of life and the ICIDH: towards an integrated conceptual model for rehabilitation outcomes research. *Clin. Rehabil.* 13, 5–15 (1999).
10. Lau A, McKenna K: Conceptualizing quality of life for elderly people with a stroke. *Disabil. Rehabil.* 23(6), 227–238 (2001).
- **Discussion of the conceptual issues related to QOL in stroke survivors and the gaps in the literature.**
11. Elavsky S, McAuley E, Motl RW *et al.*: Physical activity enhances long-term quality of life in older adults: efficacy, esteem, and affective influences. *Ann. Behav. Med.* 30(2), 138–145 (2005).
12. Low JTS, Payne S, Roderick P: The impact of stroke on informal carers: a literature review. *Soc. Sci. Med.* 49, 711–725 (1999).
- **Systematic review of 31 studies investigating the QOL of stroke caregivers.**
13. Campbell A: *The Sense of Well-Being in America*. McGraw Hill, New York, NY, USA (1981).
- **Classic book that discusses life satisfaction as a measure of overall wellbeing and the domains that influence its subjective meaning.**
14. Diener E, Emmons R, Larsen R, Griffin S: The satisfaction with life scale. *J. Pers. Soc. Psychol.* 49(1), 71–75 (1985).
15. Ferrans CE, Powers M: Quality of life index: development and psychometric properties. *Adv. Nurs. Sci.* 8(1), 15–24 (1985).
16. Ryff C: Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *J. Pers. Soc. Psychol.* 57, 1069–1081 (1989).
17. Anderson C, Laubscher S, Burns R: Validation of the Short Form 36 (SF-36) health survey questionnaire among stroke patients. *Stroke* 27, 1812–1816 (1996).
18. Van Straten A, de Haan RJ, Limburg M, Schuling J, Bossuyt PM, vanden Bos GAM: A stroke-adapted 30-item version of the Sickness Impact Profile to assess quality of life (SA-SIP30). *Stroke* 28, 2155–2161 (1997).
19. Duncan PW, Wallace D, Lai SM, Johnson D, Embretson S, Laster LJ: The stroke impact scale version 2.0. Evaluation of reliability, validity, and sensitivity to change. *Stroke* 30, 2131–2140 (1999).
20. Hawthorne G, Richardson J, Day NA: A comparison of the assessment of quality of life (AQOL) with four other generic utility instruments. *Ann. Med.* 33(5), 358–370 (2001).
21. Hilari K, Byng S, Lamping DL, Smith SC: Stroke and aphasia quality of life scale-39 (SAQOL-39). Evaluation of acceptability, reliability, and validity. *Stroke* 34, 1944–1950 (2003).
22. Buck D, Jacoby A, Massey A, Steen N, Sharma A, Ford GA: Development and validation of NEWSQOL, the Newcastle stroke-specific quality of life measure. *Cerebrovasc. Dis.* 17, 143–152 (2004).
23. Gill TM, Feinstein A: A critical appraisal of the quality-life measurements. *JAMA* 272, 619–626 (1994).
24. Doyle PJ, McNeil MR, Mikolic JM *et al.*: The Burden of Stroke Scale (BOSS) provides valid and reliable score estimates of functioning and well-being in stroke survivors with and without communication disorders. *J. Clin. Epidemiol.* 57, 997–1007 (2004).
25. Buck D, Jacoby A, Massey A, Ford G: Evaluation of measures used to assess quality of life after stroke. *Stroke* 31(8), 2004–2010 (2000).

- **Evaluation of 15 generic and ten stroke-specific instruments used to assess QOL in stroke. Includes a discussion of reliability, validity, responsiveness, precision, acceptability, suitability for proxy respondents, mode of administration and use of patient-centered approaches in development.**
- 26. Carod-Artal FJ: Specific scales for rating quality of life after stroke (Escala de calidad de vida en el ictus). *Rev. Neurol.* 3, 1052–1062 (2004). (Summary in English and article in Spanish).
- 27. Von Steinbuechel N, Richter S, Morawetz C, Riemsma R: Assessment of subjective health and health-related quality of life in persons with acquired or degenerative brain injury. *Curr. Opin. Neurol.* 18(6), 681–691 (2005).
- 28. Lucas RE, Diener E, Suh E: Discriminant validity of well-being measures. *J. Pers. Soc. Psychol.* 71(3), 616–628 (1996).
- 29. Cohen EH: A facet theory approach to examining overall and life facet satisfaction relationships. *Soc. Indic. Res.* 51(2), 223–237 (2000).
- 30. Diener E, Oishi S, Lucas RE: Personality, culture, and subjective well-being: emotional and cognitive evaluations of life. *Annu. Rev. Psychol.* 54, 403–425 (2003).
- 31. Pavot W, Diener E, Colvin CR, Sandvik E: Further validation of the satisfaction with life scale: evidence for the cross-method convergence of well-being measures. *J. Pers. Assess.* 57(1), 149–161 (1991).
- 32. Schimmack U, Diener E, Oishi S: Life-satisfaction is a momentary judgment and a stable personality characteristic: the use of chronically accessible and stable sources. *J. Pers.* 70(3), 345–384 (2002).
- 33. Lucas RE, Clark AE, Georgellis Y, Diener E: Reexamining adaptation and the set point model of happiness: reactions to changes in marital status. *J. Pers. Soc. Psychol.* 84(3), 527–539 (2003).
- 34. Hallan S, Asberg A, Indredavik B, Wideroe TE: Quality of life after cerebrovascular stroke: a systematic study of patients' preferences for different functional outcomes. *J. Intern. Med.* 246(3), 309–316 (1999).
- 35. Lindmark B, Hamrin E: A five-year follow-up of stroke survivors: motor function and activities of daily living. *Clin. Rehabil.* 9(1), 1–9 (1995).
- 36. Clarke P, Marshall V, Black SE, Colantonio A: Well-being after stroke in Canadian seniors: findings from the Canadian Study of Health and Aging. *Stroke* 33, 1016–1021 (2002).
- 37. Diener E, Diener M: Cross-cultural correlates of life satisfaction and self-esteem. *J. Pers. Soc. Psychol.* 68(4), 653–663 (1995).
- 38. Robinson-Smith G, Johnston MV, Allen J: Self-care self-efficacy, quality of life, and depression after stroke. *Arch. Phys. Med. Rehabil.* 81(4), 460–464 (2000).
- 39. De Haan RJ, Limburg M, Van der Meulen JHP, Jacobs HM, Aaronson NK: Quality of life after stroke: impact of stroke type and lesion location. *Stroke* 26, 402–408 (1995).
- 40. Moon YS, Kim SJ, Kim HC, Won MH, Kim DH: Correlates of quality of life after stroke. *J. Neurol. Sci.* 224, 37–41 (2004).
- 41. Viitanen M, Fugl-Meyer KS, Bernspang B, Fugl-Meyer AR: Life satisfaction in long-term survivors after stroke. *Scand. J. Rehabil. Med.* 20(1), 17–24 (1988).
- 42. Bays CL: Quality of life of stroke survivors: a research synthesis. *J. Neurosc. Nurs.* 33(6), 310–316 (2001).
- **Provides a synthesis of 39 articles from different countries focusing on QOL of stroke survivors during the recovery process.**
- 43. Saeki S, Chisaka H, Hachisuka K: Life satisfaction and functional disabilities in long-term survivors after first stroke. *J. Occup. Environ. Health* 27, 171–177 (2005).
- 44. Hartman-Maeir A, Soroker N, Ring H, Avni N, Katz N: Activities, participation and satisfaction one-year post stroke. *Disabil. Rehabil.* 29(7), 559–566 (2007).
- 45. Edwards DF, Hahn M, Baum C, Dromerick AW: The impact of mild stroke on meaningful activity and life satisfaction. *J. Stroke Cerebrovasc. Dis.* 15(4), 151–157 (2006).
- **Prospective study of the unanticipated consequences of mild stroke on survivors' life satisfaction.**
- 46. Saotome I: Life satisfaction and help needs in post-stroke patients. *Jpn. Geriatrics Society* 36(3), 199–205 (1999).
- 47. Johansson U, Bernspang B: Life satisfaction related to work re-entry after brain injury: a longitudinal study. *Brain Inj.* 17(11), 991–1002 (2003).
- 48. Vestling M, Tufvesson B, Iwarsson S: Indicators for return to work after stroke and the importance of work for subjective well-being and life satisfaction. *J. Rehabil. Med.* 35(3), 127–131 (2003).
- 49. Vestling M, Ramel E, Iwarsson S: Quality of life after stroke: well-being, life satisfaction, and subjective aspects of work. *Scand. J. Occup. Ther.* 12(2), 89–95 (2005).
- 50. Teasell RW, McRae MP, Finestone HM: Social issues in the rehabilitation of younger stroke patients. *Arch. Phys. Med. Rehabil.* 81(2), 205–209 (2000).
- 51. Hinckley JJ: Vocational and social outcomes of adults with chronic aphasia. *J. Commun. Disord.* 35(6), 543–560 (2002).
- 52. Treger I, Shames J, Giaquinto S, Ring H: Return to work in stroke patients. *Disabil. Rehabil.* 29(17), 1397–1403 (2007).
- 53. Segal ME, Schall RR: Life satisfaction and caregiving stress for individuals with stroke and their primary caregivers. *Rehabil. Psychol.* 41(4), 303–320 (1996).
- 54. Kauhanen ML, Korpelainen JT, Hiltunen P, Nieminen P, Sotaniemi KA, Myllylä VV: Domains and determinants of quality of life after stroke caused by brain infarction. *Arch. Phys. Med. Rehabil.* 18(12), 1541–1546 (2000).
- 55. Suenkel IH, Nowak M, Misselwitz B et al.: Timecourse of health-related quality of life as determined 3, 6 and 12 months after stroke: relationship to neurological deficit, disability and depression. *J. Neurol.* 249(9), 1160–1167 (2002).
- 56. Hopman WM, Verner J: Quality of life during and after inpatient stroke rehabilitation. *Stroke* 34(3), 801–805 (2003).
- 57. Jonsson AC, Lindgren I, Hallstrom B, Norrving B, Lindgren A: Determinants of quality of life in stroke survivors and their informal caregivers. *Stroke* 36, 803–808 (2005).
- 58. Clarke PJ, Lawrence JM, Black SE: Changes in quality of life over the first year after stroke: findings from the Sunnybrook Stroke Study. *J. Stroke Cerebrovasc. Dis.* 9, 121–127 (2000).
- 59. Darlington ASE, Dippel DWJ, Ribbers GM, Van Bale R, Passchier J, Busschbach JJV: Coping strategies as determinants of quality of life in stroke patients: a longitudinal study. *Cerebrovasc. Dis.* 23(5–6), 402–407 (2007).
- **Discussion of specific coping strategies that affect QOL.**
- 60. Giaquinto S, Spiridigliozzi C, Caracciolo B: Can faith protect from emotional distress after stroke? *Stroke* 38, 993–997 (2007).
- 61. Gargano JW, Reeves MJ: Sex differences in stroke recovery and stroke-specific quality of life: Results from a statewide stroke registry. *Stroke* 38, 2541–2548 (2007).
- 62. Teasdale TW, Engberg AW: Psychological consequences of stroke: a long-term population-base follow-up. *Brain Inj.* 19(12), 1049–1058 (2005).

- **Discusses the psychological consequences of stroke on a national representative sample of Danish stroke survivors at 5, 10 and 15 years poststroke.**
- 63. Carlsson GE, Forsberg-Warley G, Moller A, Blomstrand C: Comparison of life satisfaction within couples one year after a partner's stroke. *J. Rehabil. Med.* 39(3), 219–224 (2007).
- **Comparison of life satisfaction at 1 year in stroke survivors and spousal caregivers with suggestions for individualizing approaches to meet different needs.**
- 64. Forsberg-Warley G, Moller A, Blomstrand C: Spouses of first-ever stroke patients: psychological well-being in the first phase after stroke. *Stroke* 32, 1646–1651 (2001).
- 65. Visser-Meily A, Post M, Schepers V, Lindeman E: Spouses' quality of life 1 year after stroke: prediction at the start of clinical rehabilitation. *Cerebrovasc. Dis* 20(6), 443–448 (2005).
- 66. Neiboer AP, Schulz R, Matthews KA, Scheier MF, Obmel J, Lindenberg SM: Spousal caregivers' activity restrictions and depression: a model for changes over time. *Soc. Sci. Med.* 47, 1361–1371 (1998).
- 67. Forsberg-Warley G, Moller A, Blomstrand C: Spouses of first-ever stroke victims: sense of coherence in the first phase after stroke. *J. Rehabil. Med.* 34(3), 128–133 (2002).
- 68. Forsberg-Warley G, Moller A, Blomstrand C: Life satisfaction in spouses of patients with stroke during the first year after stroke. *J. Rehabil. Med.* 36(1), 4–11 (2004).
- 69. Pinquart M, Sorensen S: Associations of caregiver stressors and uplifts with subjective well-being and depressive mood: a meta-analytic comparison. *Aging Ment. Health* 8(5), 438–449 (2004).
- **Meta-analysis of 60 studies on informal caregivers' depression and subjective wellbeing, based on a two-factor model distinguishing between positive and negative dimensions of wellbeing.**
- 70. Bethoux F, Calmels P, Gautheron MP, Minaire P: Quality of life of the spouse of stroke patients: a preliminary study. *Int. J. Rehabil. Res.* 19, 291–299 (1996).
- 71. White CL, Poissant L, Cote-LeBlanc G, Wood-Dauphinee S: Long-term caregiving after stroke: the impact on caregivers' quality of life. *J. Neurosci. Nurs.* 38(5), 354–360 (2006).
- 72. Kauhanen, M, Korpelainen JT, Hiltunen P *et al.*: Poststroke depression correlates with cognitive impairment and neurological deficits. *Stroke* 30, 1875–1880 (1999).
- 73. Gaete JM, Bogousslavsky J: Post-stroke depression. *Expert Rev. Neurother.* 8(1), 75–92 (2008).
- 74. Kim P, Warren S, Madill H, Hadley M: Quality of life of stroke survivors. *Qual. Life Res.* 8(4), 293–301 (1999).
- 75. Ormel J, Kempen GIJM, Deeg DJH, Brilman EI, Van Sonderen E, Relyveld J: Functioning, well-being, and health perception in late middle-aged and older people: comparing the effects of depressive symptoms and chronic medical conditions. *J. Am. Geriatr. Soc.* 46(1), 39–48 (1998).
- 76. Xu B-H, Hu Y-H: Quality of life in stroke patients. *Chinese J. Clin. Rehabil.* 9(1), 136–138 (2005).
- 77. King R: Quality of life after stroke. *Stroke* 27, 1467–1472 (1996).
- 78. Jonkman EJ, De Weerd AW, Vrijens NLH: Quality of life after a first ischemic stroke long-term developments and correlations with changes in neurological deficit, mood and cognitive impairment. *Acta Neurol. Scand.* 98(3), 169–175 (1998).
- 79. Mackenzie A, Chang A: Predictors of quality of life following stroke. *Disabil. Rehabil.* 24(5), 259–265 (2002).
- 80. Carod-Artal FJ, Egidio JA, Gonzalez JL, Seijas EV: Quality of life among stroke survivors evaluated 1 year after stroke: experience of a stroke unit. *Stroke* 31(12), 2994–3000 (2000).
- 81. Sturm JW, Donnan GA, Dewey HM *et al.*: Quality of life after stroke: the North East Melbourne Stroke Incidence Study (NEMESIS). *Stroke* 35, 2340–2345 (2004).
- 82. Lofgren B, Gustafson Y, Nyberg L: Psychological well-being 3 years after severe stroke. *Stroke* 30, 567–572 (1999).
- 83. Evans RL, Connis RT, Bishop DS, Hendricks RD, Haselkorn JK: Stroke: a family dilemma. *Disabil. Rehabil.* 16, 110–118 (1994).
- 84. Anderson CS, Linto J, Stewart-Wynne EG: A population-based assessment of the impact and burden of caregiving for long-term stroke survivors. *Stroke* 26, 843–849 (1995).
- 85. Elmstahl S, Malmberg B, Annerstedt L: Caregiver's burden of patients 3 years after stroke assessed by a novel caregiver burden scale. *Arch. Phys. Med. Rehabil.* 77(2), 177–182 (1996).
- 86. Kotila M, Numminen H, Walima O, Kaste M: Depression after stroke: results of the FINNSTROKE study. *Stroke* 29, 368–372 (1998).
- 87. Draper P, Brocklehurst H: The impact of stroke on the well-being of the patient's spouse: an exploratory study. *J. Clin. Nurs.* 16(2), 264–271 (2007).
- 88. Franzen-Dahlin A, Larson J, Murray V, Wredling R, Billing E: Predictors of psychological health in spouses of persons affected by stroke. *J. Clin. Nurs.* 16, 885–891 (2007).
- 89. Larson J, Franzen-Dahlin A, Billing E, von Arbin M, Murray V, Wredling R: The impact of gender regarding psychological well-being and general life situation among spouses of stroke patients during the first year after the patients' stroke event: a longitudinal study. *Int. J. Nurs. Stud.* 45(2), 257–265 (2008).
- 90. Yacer A, Zunzunegui MV, Gutierrez-Cuadra P, Beland F, Zarit SH: Correlates of wellbeing of spousal and children carers of disabled people over 65 in Spain. *Eur. J. Public Health* 12(1), 3–9 (2002).
- 91. Blake H, Lincoln NB, Clarke DD: Caregiver strain in spouses of stroke patients. *Clin. Rehabil.* 17(3), 312–317 (2003).
- 92. Schulz R, Beach SR: Caregiving as a risk factor for mortality. *JAMA* 282, 2215–2219 (1999).
- 93. Grant JS, Bartolucci AA, Elliot TR, Giger JN: Sociodemographic, physical, and psychosocial characteristics of depressed and non-depressed family caregivers of stroke survivors. *Brain Inj.* 14(12), 1089–1100 (2000).
- 94. Thompson SC: The search for meaning following a stroke. *Basic Appl. Soc. Psych.* 12(1), 81–96 (1991).
- 95. Archbold PG, Stewart BJ, Greenlick MR, Harvath TA: Mutuality and preparedness as predictors of caregiver role strain. *Res. Nurs. Health* 12, 375–384 (1990).
- 96. Antonovsky A: The moral and the healthy: identical, overlapping or orthogonal? *Isr. J. Psychiatry Relat. Sci.* 32(1), 5–13 (1995).
- 97. Haley WE, LaMonde LA, Han B, Burton AM, Schonwetter R: Predictors of depression and life satisfaction among spousal caregivers in hospice: application of a stress process model. *J. Palliat. Med.* 6(2), 215–224 (2003).
- 98. Nilsson I, Axelsson K, Gustafson Y, Lundman B, Norberg A: Well-being, sense of coherence, and burnout in stroke victims and spouses during the first few months after stroke. *Scand. J. Caring Sci.* 15(3), 203–214 (2001).
- 99. Palmer S, Glass T: Family function and stroke recovery: a review. *Rehabil. Psychol.* 48, 255–265 (2003).

100. Korpelainen JT, Nieminen P, Myllylä VV: Sexual functioning among stroke patients and their spouses. *Stroke* 30, 715–719 (1999).
101. Blonder LX, Langer SL, Pettigrew LC, Garrity TF: The effects of stroke disability on spousal caregivers. *NeuroRehabilitation* 22(2), 85–92 (2007).
102. Kulik L: Attitudes toward spousal caregiving and their correlates among aging women. *J. Women Aging* 13(3), 41–58 (2001).
103. Clark MS, Smith DS: Changes in family functioning for stroke rehabilitation patients and their families. *Int. J. Rehabil. Res.* 22(3), 171–179 (1999).
104. Eriksson GK, Tham K, Fugl-Meyer AR: Couples' happiness and its relationship to functioning in everyday life after brain injury. *Scand. J. Occup. Ther.* 12(1), 40–48 (2005).
105. Grant JS, Elliott TR, Giger JN, Bartolucci AA: Social problem-solving abilities, social support, and adjustment among family caregivers of individuals with a stroke. *Rehabil. Psychol.* 46(1), 44–57 (2001).
106. Smout S, Koudstaal P, Ribbers G, Janssen W, Passchier J: Struck by stroke: a pilot study exploring quality of life and coping patterns in younger patients and spouses. *Int. J. Rehabil. Res.* 24(4), 261–268 (2001).
107. Studenski S, Duncan PW, Perera S, Reker D, Lai SM, Richards L: Daily functioning and quality of life in a randomized controlled trial of therapeutic exercise for subacute stroke survivors. *Stroke* 36, 1764–1770 (2005).
- **Randomized, controlled trial of an exercise program for stroke survivors that produced changes in stroke-specific QOL measures.**
108. Hellstrom K, Lindmark B, Wahlberg B, Fugl-Meyer AR: Self-efficacy in relation to impairments and activities of daily living disability in elderly patients with stroke: a prospective investigation. *J. Rehabil. Med.* 35(5), 202–207 (2003).
109. Gabaldon L, Fuentes B, Frank-Garcia A, Diez-Teodor E: Poststroke depression: Importance of its detection and treatment. *Cerebrovasc. Dis.* 24(Suppl. 1), 181–188 (2007).
110. Rombough, RE, Howse EL, Bagg SD, Bartfay WJ: A comparison of studies on the quality of life of primary caregivers of stroke survivors: a systematic review of the literature. *Top. Stroke Rehabil.* 14(3), 69–79 (2007).
- **Systematic review of nine studies of caregivers of stroke survivors using different nonstroke-specific instruments to assess QOL.**
111. Nir Z, Zolotogorsky Z, Sugarman H: Structured nursing intervention versus routine rehabilitation after stroke. *Am. J. Phys. Med. Rehabil.* 83(7), 522–529 (2004).
- **Intervention study demonstrating better outcomes when caregivers are involved early in the rehabilitation process.**
112. Kalra L, Evans A, Perez I *et al.*: Training carers of stroke patients: randomised controlled trial. *Br. Med. J.* 328(7448), 1099 (2004).
- **Randomized, controlled trial of a caregiving intervention during rehabilitation demonstrated positive outcomes for stroke survivors and caregivers 1 year later.**
113. Pierce LL, Steiner V, Govoni AL: In-home online support for caregivers of survivors of stroke: a feasibility study. *Comput. Inform. Nurs.* 20(4), 157–164 (2002).
114. Bakas T, Austin JK, Jessup SL, Williams LS, Oberst MT: Time and difficulty of tasks provided by family caregivers of stroke survivors. *J. Neurosci. Nurs.* 36(2), 95–106 (2004).
115. Wilz G, Barskova T: Evaluation of a cognitive behavioral group intervention program for spouses of stroke patients. *Behav. Res. Ther.* 45(10), 2508–2517 (2007).
- **Experimental study demonstrating short-term and long-term improvements in depression and QOL in spousal caregivers.**
116. Sorensen S, Pinquart M, Duberstein P: How effective are interventions with caregivers? An updated meta-analysis. *Gerontologist* 42(3), 356–372 (2002).
- **Meta-analysis of 78 caregiver intervention studies (not stroke specific) categorized into six categories: psychoeducational interventions, supportive interventions, respite/adult day care, psychotherapy, interventions to improve carereceiver competence and multicomponent interventions.**
117. Lee JH, Soeken K, Picot SJ: A meta-analysis of interventions for informal stroke caregivers. *West. J. Nurs. Res.* 29(1), 344–356 (2007).
- **Meta-analysis of four (out of 31) intervention studies of stroke caregivers that showed improvements in caregiver mental health.**
118. Fang J, Alderman MH: Trend of stroke hospitalization, United States, 1988–1997. *Stroke* 32, 2221–2226 (2001).
119. Mayo NE, Wood-Dauphinee S, Ahmed S: Disablement following stroke. *Disabil. Rehabil.* 21(5–6), 258–268 (1999).
120. National Alliance for Caregiving/AARP: Family Caregiving in the US: findings from a national survey. Washington DC, USA (1997).
121. Schulz RJ, Newsom, Mittlemark M, Burton L, Hirsch C, Jackson S: Health effects of caregiving: the caregiver health effects study: an ancillary study of the Cardiovascular Health Study. *Ann. Behav. Med.* 19(2), 110–6, (1997).
122. Gitlin LN, Belle SH, Burgio LD *et al.*: Effect of multicomponent interventions on caregiver burden and depression: the REACH multisite initiative at 6-month follow-up. *Psychol Aging* 18(3), 361–374 (2003).
- **Meta-analysis of nine caregiver intervention studies that were a part of the National Institutes of Health-funded Resources for Enhancing Alzheimer's Caregiver Health (REACH) project, demonstrating the importance of active, tailored multicomponent intervention studies.**

Websites

201. Mackay J, Mensah G: The Atlas of Heart Disease and Stroke. Geneva, Switzerland: World Health Organization (2004). www.who.int/cardiovascular_diseases/resources/atlas/en/
- **Excellent overview of cardiovascular disease (including stroke), risk factors, burden of disease worldwide and action, in terms of research, treatment, policy and legislation. It also includes a very interesting timeline of knowledge of heart and vascular disorders from a drawing in the Paleolithic era to 2004. There is also a World Data Table that includes stroke disability (disability-adjusted life years) for 2003 and stroke mortality rates for 2002 for 192 countries.**
202. American Heart Association: Heart Disease and Stroke Statistics – 2008. www.americanheart.org/presenter.jhtml?identifier=1928
- **Accurate and current website with information and resources for stroke survivors, family caregivers and healthcare professionals.**
203. Jones VN: The Forgotten Survivor. (Electronic version). Stroke Smart (2006). www.stroke.org/site/PageServer?pagename=SS_MAG_so2006_feature_forgot
204. Administration on Aging: A Profile of Older Americans. US Department of Health and Human Services, Bethesda, MD, USA (2006). www.aoa.gov/prof/Statistics/profile/2006/2006profile.doc