THEORY OF QUALITY OF LIFE OF STROKE SURVIVORS (TQLOSS)

by

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To my mother, Amay Fraser, whose love of education inspired me to strive for the best and highest level of education, even though her own education stopped at the seventh standard (grade). And to my daughters Elizabeth and Keke who encouraged me to pursue a dream deferred.

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CHAPTER 1

INTRODUCTION

The purpose of this study is to develop and test a model of a middle-range theory of quality of life in stroke survivors (TQOLSS) derived from King's (1981) Interacting Systems Framework for Nursing (ISFN). Concepts that will be used in this study are 1) perceptual integrity derived from perception in the personal system; 2) social support as interaction, derived from the interpersonal system; 3) perception of level of disability derived from self in the personal system; and 4) health-related quality of life derived from health in the personal system. Quality of life (QOL) is viewed as an important health care outcome (Frey, 2001; Fuhrer, 1994). A stroke is frequently viewed as a personal disaster, by both the individual and the family, which hits the individual suddenly and in its wake leaves a traumatic and disabling sequelae. Studies that have looked at life satisfaction/quality of life post stroke have not been done within a nursing theoretical framework. Testing of hypotheses about proposed relationships among these variables, and examination of the contribution of age, time since stroke and number of strokes will also be done.

Background

According to the American Heart Association (AHA) a cerebrovascular accident (CVA), commonly known as stroke or brain attack, is the third leading cause of death and a leading cause of serious long-term disability in the United States (AHA, 2002). The incidence of stroke among Blacks under the age of 65 is two to four times greater than that reported for whites, and for those over the age of 65, the incidence is the same as for whites (Broderick, et al., 1998). Persons over age 65 accounts for 72% of all strokes. Long-term survivorship is better among women than men and strokes are more prevalent in blacks than whites. Strokes account for more than half of all patients hospitalized for acute neurological diseases (AHA, 2002). The incidence and prevalence of stroke increased in the 1980s especially in those 65 years of age and over (Stegmayr, Asplund & Wester, 1994; Wolf et al., 1992). Scientific and technological advances in medical care have increased the life expectancy. Along with the increase life expectancy is a decrease in mortality and an increase in survivorship for many illnesses including strokes. Mortality from stroke has decreased during the same time frame, giving rise to an increase in stroke survivorship (Barker & Mullooly, 1997; Shahar et al., 1995; Wolf & D'Agostino, 1998). The number of stroke survivors rose from 3,080,000 in 1992 to about 4,600,000 in 2001 (AHA, 1995, 2002). Sixteen percent of these stroke survivors have required institutionalization, 31% need help with self-care, 20% require help with ambulation, and 71% are vocationally impaired (Elias, D'Agostino, Elias, & Wolf, 1995).

Researchers have suggested several mechanisms that have contributed to the decline in stroke mortality and the increase in stroke survivorship. These are: (1) Increased awareness and early recognition of transient ischemic attacks (TIAs) by the general population and physicians, which would explain the increase in the incidence of total cerebrovascular events and a concomitant decrease in the case fatality rate (Shahar et al., 1995; Wolf et al., 1992); (2) A decline in the incidence of intracerebral and subarachnoid hemorrhages (SAH) that have high case fatality (Wolf et al., 1992); (3) Widespread use of computed tomography (CT) which improved diagnostic sensitivity and specificity thus increasing the detection of milder cases and increasing the apparent incidence of strokes (Broderick et al., 1989; Brown, Whisnant, Sicks, O'Fallon, & Wiebers, 1996; Shahar et al; Wolf et al.); (4) Better control of diabetes (Stegmayr et al., 1994); (5) Widespread use of aspirin among individuals at risk for strokes (Stegmayr et al.); (6) Improved nutrition with greater use of antioxidants (Stegmayr et al.); (7) Early detection and treatment of hypertension and other contributing factors (Broderick et al., 1989); and (8) Improved management of stroke patients (Shahar et al; Stegmayr et al.). Trials of neuroprotectants and thrombolytics are ongoing therefore; their role in decreasing stroke mortality and increasing stroke survivorship is still being evaluated (National Stroke Association, 1999; Wardlaw, del Zoppo, & Yamaguchi, 2000; Qizilbash, Lewington, & Lopez-Arrieta, 2000).

The stroke survivor faces many challenges because of the impairments that are secondary to the stroke. Common impairments are hemiplegia, hemiparesis, ataxia, hemisensory alteration, neglect of involved extremities, homonymous hemianopia, loss of depth perception, double vision, nystagmus, dysphasia, dysgraphia, aphasia, perseveration, confusion, shortened attention span, loss of mental acuity, short term memory loss, impulsivity, problems conceptualizing and generalizing, and bowel and bladder incontinence (Schnell, 1997). These limitations may cause major changes in the individual and affect their ability to perform usual roles and self-care activities. The individual's perception of what is happening to them can also be altered secondary to the impairments sustained. According to King (1981), an internally altered nervous system alters perceptions. Alterations in one's perceptual system may affect one's self-identity, interaction with others and health.

The World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) has two components: 1) functioning and disability, which is divided into body functions and structure, and activities and participation, and 2) contextual factors, which is divided into environmental factors and personal factors (WHO, 2001). According to ICF impairments are problems in body function or structure such as a significant deviation or loss. Impairments can be temporary or permanent; progressive, regressive or static; intermittent or continuous. Impairments may be part or an expression of a health condition, but is not necessarily an indication that a disease is present or that the individual should be regarded as sick. Impairments may result in other impairments; for example, hemiplegia may impair movement. Activity is the execution of a task or action by an individual. Activity limitation is, therefore, difficulties that an individual may have in performing a task. Participation is involvement in a life situation. Participation restrictions are problems that an individual may experience in involvement in life situations. Environmental factors make up the physical, social and structural environment in which people live and conduct their lives. Personal factors are the particular background of the individual's life and living, and comprise features of the individual that are not part of the health condition or health states. Age, gender, other health conditions, lifestyle, coping styles, education, past and current experience, and overall behavior patterns are some personal factors. Disability is an umbrella term for impairments, activities limitations or participation restrictions. Disability is characterized as the outcome or result of a complex relationship between an individual's health condition and personal factors, and of the external factors that represent the circumstance in which the individual lives. Environmental and personal factors can therefore facilitate or hinder the individual's performance of tasks. According to this model of disablement, personal and environmental factors, such as socioeconomic status and education, culture and the physical environment, can influence disability experience of the individual (WHO, 2001, pp. 10-20). Other models of disablement (Nagi, 1976; Verbrugge & Jette, 1994) include the concepts of impairment, functional impairment and disability.

Two individuals with the same impairments can have very different disability experiences. Stephen Hawking, who is very dependent on others for all his activities of daily living (ADLs) yet continues to function as a scientist is a good illustration of the role that environmental and personal factors play in disability. The Americans with Disabilities Act (ADA) indicates the commitment of the government to the removal of obstacles to the integration of people with disabilities into everyday society (ADA, 1990).

In addition to impairments, the stroke survivor and family have to deal with the financial impact of the event. The financial losses for the individual, the family, and society are quite high. Strokes cost an estimated $49.4 billion in 2002. Direct cost of strokes included $24.5 billion for hospital/nursing homes, $2.4 billion for physicians/other professionals services, $0.8 billion for drugs, and $3.1 billion for home health/other medical durables for a total of $30.8 billion. Indirect costs for lost productivity due to morbidity and mortality was estimated as $18.6 billion (AHA, 2002).

After initial hospitalization over 80% of stroke survivors return to the community (Elias et al., 1995) and rely on the emotional, informational and instrumental support of their families/caregivers for daily living (Anderson, Linto, & Stewart-Wynne, 1995). The families/caregivers of stroke survivors experience other burdens in addition to financial costs. Han and Haley (1999) reviewed 20-stroke caregiving research articles published between 1986 and 1998 and reported that there was a high rate of depression in stroke caregivers, much higher than in both available norms and other comparison control groups. They cautioned, "Most stroke caregiving studies have the common characteristics of small sample sizes and opportunistic samples with selection bias" (p. 1479). Financial problems were reported by families in which the main wage earner was the stroke survivor and among those providing care for the stroke survivor (Anderson et al., 1995; Greveson, Gray, French, & James, 1991; Periard & Ames, 1993). Emotional ill health including anxiety, depression, fear, frustration, resentment, impatience and guilt, and social isolation due to disruption of social activities and leisure time were also reported by families/caregivers (Anderson et al.; Greveson et al.; Periard & Ames; Scholte op Reimer, de Haan, Rijnders, Limburg, & van den Bos, 1998).

Another area of families'/caregivers' life affected by caregiving was family relationships, that were manifested by tension, misunderstanding or feelings of neglect among the family members due to the physical and emotional demands of the stroke survivor (Anderson et al., 1995; Periard & Ames, 1993). However, some reported closer relationships with family (Periard & Ames). Families/caregivers experienced physical symptoms, such as insomnia, or interference with management of their own health (Anderson et al.; Greveson et al., 1995), changes in dietary habits, improved for some, while others had problems with overeating or inability to eat (Periard & Ames), and changes in instrumental activities of daily living ([IADL], Periard & Ames). In a case, study the family reported role changes with resultant role conflict, and alterations in retirement plans (Jongbloed, 1994).

Studies of stroke outcomes have looked at functionality (Glass & Maddox, 1992; Glass, Matchar, Belyea & Feussner, 1993; Jongbloed, 1986; Lindmark & Hamrin, 1995), discharge disposition (Brodie, Holm, & Tomlin, 1994; Brosseau, Potvin, Phillipe, & Boulanger, 1996; Colantonio, Kasl, Ostfeld, & Berkman, 1993), psychosocial functioning (Aström, Adolfsson & Asplund, 1993; Friedland & McColl, 1987; Clark & Smith, 1998; Herrmann, Black, Lawrence, Szekely, & Szalai 1998), and life satisfaction/quality of life (Ahlsiö, Britton, Murray, & Theorell, 1984; Aström, Asplund, & Aström, 1992; King, 1996; Neimi, Laaksonen, Kotila & Waltimo, 1988). Some qualitative studies examined the experiences of stroke survivors with various types of strokes, focusing on their perceptions of the effects of the stroke. Most survivors did not focus on what functions they had but rather on what losses they had experienced and what the loss of functions meant to them (Doolittle, 1991; Folden, 1994; Mumma, 1986; Secrest & Thomas, 1999; Jongbloed, 1994). A longitudinal study to evaluate the psychosocial and health status of stroke survivors after 14 years looked at the socioeconomic situation, self-reported functional capacity, psychosomatic status, perceived mental status and perceived health (Tuomilehto et al., 1995). They reported that over 80% of the stroke survivors lived at home or with relatives. Functional capacity was good in about two thirds of the participants, and only 10% to 15% felt depressed. About half of both men and women aged 64 years or younger perceived their health as good, while only 25% of men aged 65 years or over did.

Patients who were having ultrasound evaluation of their carotid arteries were asked to rank their preferences for four categories of stroke severity (mild, moderate, severe, and fatal), and for nonfatal strokes (Solomon, Glick, Russo, Lee, & Schulman, 1994). The 117 participants with a mean age of 73 were given scenarios describing motor, language, and cognitive deficits. A rank-and-scale method over a 100-point range was used for the 10 scenarios, with 100 representing perfect health and 0 corresponding to the worst possible health state. The acceptability by the subjects of mild and moderate deficits varied; however, severe deficits were rated as uniformly undesirable. Subjects scored the dense disabling hemiplegia as significantly worse than general confusion, global aphasia, and death. The authors suggested that the findings might reflect a fear of dependence and isolation among the elderly urban cohort who rely heavily on mobility to preserve their autonomy. Although this study did not specifically measure QOL, patients preferences were clearly related to preferred health state, which is a factor in QOL.

Strokes affect the financial, psychosocial, and physical well-being of both the stroke survivors and their families/caregivers, which affect their QOL. The goal of rehabilitation has shifted from the restoration of function and integration of persons with disabilities into society to enhancing their QOL. Seton (1993) noted that a goal of Rehabilitation International is "to improve the QOL of people with disabilities throughout the world" (p. 10). QOL outcomes are concerned with the functional and psychosocial factors in the individual's life and provide nurses with information that can be used for goal setting.

There is great diversity in the definitions of quality of life (QOL). The World Health Organization Quality of Life (WHOQOL) Group defines QOL as individuals perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHOQOL Group, 1995). Schipper, Clinch, and Olweny, (1996) defines it as the patient's perceptions of performance in four areas (physical and occupational, psychological, social interaction, and somatic sensation). These definitions view QOL as a subjective evaluation that is embedded in a cultural, social and environmental context. Health-related quality of life (HRQOL) is seen as a subset of the overall concept of QOL. HRQOL includes the domains of physical, psychological, social, spiritual, and role functioning, as well as general well-being (Spilker & Revicki, 1996). Unlike the definitions of QOL by the WHOQOL Group and Schipper et al., the individual's perception was not included in the definition of HRQOL by Spilker and Revicki. Although there are various conceptualizations of HRQOL, there is consensus that these domains are necessary for any comprehensive definition of HRQOL. Most other definitions of QOL include the individual's degree of satisfaction and/or perception of satisfaction with life (Andrews, 1974; Haas, 1999, Hornquist, 1982; Oleson, 1990; Zahn, 1992).

Nursing has a long-standing tradition of learning as much as possible about what patients and their families find meaningful in their lives and how health fits in with these personal perceptions (Hinds & Varricchio, 1996). Nurses are concerned not only with the individual's functional ability, but also with their sense of well-being. The goal of rehabilitation nursing is maintenance of function through primary prevention of disability and the restoration of optimum function in performance of self-care and social roles (Dittmar, 1989). According to King, health has a high priority in the hierarchy of values in society (1981, p. 4). King indicates that measurement of health is a world wide concern and that the traditional indicators of health, such as mortality and morbidity are not adequate as they do not recognize the social, emotional, or economic consequences of illness, nor measure the effects of chronic diseases. King suggested that measurements of health should include attributes that are essential for human beings to function in their roles, environmental factors and the development process (p.6).

The ability to maintain a level of health that enables one to perform activities of daily living and lead a relatively useful, satisfying, productive and happy life is one of life's challenges (King, 1981, 1990). King (1994) further states that health is implied as a factor in life that allows one to function in one's usual roles. QOL is an important outcome that is used in making treatment decisions and allocation of resources for health care (Goodinson & Singleton, 1989). According to King, (1981) human beings need usable information at a time when they require it and are able to use it. QOL assessments provide information about the benefits and side effects of diagnostic procedures and treatments, which can help the individual to make decisions that are congruent with their values and beliefs about life. King (1994) indicates discussing QOL can be one of the essential elements in the human interaction process that leads to goal setting by individuals, families, and society. Goal setting includes factors such as shared values, clear communication, and appropriate and adequate information for decision-making. Goal setting in most instances leads to goal attainment, which leads to satisfaction and to the perception of one's ability to accomplish things in life (p.29).

Working as a rehabilitation nurse this investigator observed the emphasis that is placed on functional outcomes and performance of ADLs with little or no emphasis on the performance of roles and QOL. This investigator also observed during home visits that many stroke survivors spent their days watching television. These observations are the impetus for this study of QOL in stroke survivors.

The Problem

Historically the evaluation of stroke outcomes have looked at loss of function, with interest in the psychological aspects increasing since the mid nineteen-eighties. There is extensive literature that has looked at the functional and psychosocial outcomes of stroke. Studies have also looked at the factors that influence QOL poststroke. No studies of stroke outcome that looked at the relationships among perceptual integrity, perception of level of disability, social support and perception of HRQOL and used a nursing conceptual framework were found.

Nursing is in the process of creating a unique body of knowledge to guide its practice. However, there is concern that the majority of the research conducted by nurse researchers is not nursing research and it does not advance nursing science. Fawcett (1999) argues that much of the research conducted by nurses is "guided by nonnursing conceptual frameworks, theories and methodologies" (p. 313). The science of nursing should have practice theories that are conceptually based and empirically tested. The literature reveals that no studies by nurses have utilized a nursing theoretical framework for studying stroke outcome. The grand theories of nursing provide a conceptual framework for the development and testing of middle-range and micro theories to provide the empirical evidence upon which nursing practice can be based. Significant findings in this study would provide empirical support for the conceptualizations of King's conceptual framework. These findings would also provide clinicians with the empirical evidence needed for the development of clinical interventions.

CHAPTER 2

LITERATURE REVIEW

This literature review will focus primarily on empirical research related to QOL of stroke survivors. Studies that have examined life satisfaction, psychological well-being, and subjective well-being post stroke, terms commonly used to refer to QOL will also be reviewed. The literature is from nursing and related disciplines. Studies are reported historically from the oldest to the most recent.

The experience of QOL post stroke in 27 men and 18 women, whose ages ranged from 36 to 86 years, was explored in a qualitative study in Australia (Lawrence & Christie, 1979). Thirteen of the participants were born overseas and eight did not speak English. Interviews were held with each subject and a relative or close friend, usually separately and then together.

The subjects level of disability was classified according to the Rankin Scale. In this study, the first and second levels (no significant disability and slight disability respectively) were combined to form a minimal disability group. The third and fourth levels, where assistance was needed for some activities of daily living (ADL) including walking in the fourth level, were combined to form a moderate disability group. There were no survivors at the fifth level (chair or bed-fast). In the minimal disability level group, there were 14 patients below the age of 60 years, and 11 over the age of 60; in the moderate disability group, there were three below age 60 and 17 over age 60.

The reactions of the individuals towards their illness and consequent disability were explored and their responses grouped into two main categories with two subcategories each.

A. Appropriate
    (i) Coping as before: physical disability was absent or minimal, and the subject's life situation did not appear to have been affected.

> (ii) Realistic response: frank acknowledgement of disability and change, with definite and suitable efforts to cope with difficulties.
>
> B. Inappropriate
>
> (iii) Unrealistic response: reaction to change not based on reality. Includes denial or exaggeration of problems with little or no constructive effort having been made to adapt to difficulties.
>
> iv) Severely disturbed response: gross behavioral disturbances with little grasp of reality (p. 168).

The results indicated that over half the subjects (24) had an inappropriate response to their situation, and 44% were in the minimal disability group. However, there was no significant relationship between disability and appropriateness of response. Site of lesion and appropriateness of response were not associated. The subjects' attitudes about the future were explored as a guide to their general outlook on life. These attitudes were broadly grouped as "pessimistic, uncertain, or optimistic" and classified by disability and appropriateness of response. A significant association was found between minimal disability and an optimistic view of the future, however, over half the subjects in the minimal disability group were uncertain or pessimistic. A strong association also was reported between inappropriateness of response and a pessimistic view.

The effect of the stroke on occupation affected the eight non-English speaking migrants most of all; five men and the one woman in this group who were previously employed did not resume work of any kind, and became quite dependent upon their spouses. In the moderate disability group, only one subject continued with the same leisure pattern as before. Half of the members of this group had completely withdrawn from all but the most passive interest. The less disabled were less affected but three individuals had withdrawn entirely from leisure pastimes.

The authors concluded that strokes devastated many of the subjects lives: they ceased working prematurely, their interpersonal relationships had deteriorated, and over 70% viewed their future with uncertainty or gloom. Physical disability in itself was less important than the subjects response to their disability, with inappropriate and dysfunctional responses present in over half the subjects.

The influence of disablement and emotional factors on the quality of life of 96 stroke survivors in Sweden was examined by Ahlsiö, Britton, Murray and Theorell (1984). The participants ranged in age from 35 to 90 years and 60% were males. The stroke types were: hemorrhage 5%, thrombosis 60%, embolism 11%, TIA 22%, and unspecified 2%. At discharge, 55 of the 96 subjects returned home and 41 were transferred to geriatric hospitals for further rehabilitation. Forty-six subjects were married, 16 were single or divorced and 34 were widowed. Fifty-two lived with other persons, 15% were of the highest socioeconomic group, 42% were middle class and 43% were workers. Twenty subjects worked outside the home and the remaining subjects were housewives or had old age pensions. At the end of the study 26 subjects had died, 54 were living at home and 16 in geriatric hospitals. Causes of death were complications of the initial stroke (5); new stroke (10); ischemic heart disease (5); aortic aneurysm, gangrene (3); and neoplasm, uremia (3). Twenty-two subjects suffered subsequent strokes.

ADL was measured by the Katz Index, and QOL by bars graded with "worst possible" at the bottom and "best possible" at the top. The subjects were asked to mark on the left bar his/her QOL before the stroke and on the right bar his/her present one. There was no access to earlier graphs when reexamined. The difference in height before and after stroke was calculated. This provided a measure of change rather than a static condition. Changes in quality of life marked on the bars were validated against interview answers regarding their total life situation (i.e. constant, changed or deteriorated).

The ADL capacity of the whole group improved gradually with time. At the acute stage, 55% were in the independent group compared to 76% at the end of the study. There was some deterioration in ADL due to gradual worsening in two subjects who were in a bad condition at the beginning, some were due to new strokes, broken leg, other accidents and leg amputations. In the acute stage, older subjects had a tendency to be somewhat worse in ADL. Age and initial ADL were significantly important at the end of the two years, with younger subjects with independent ADLs having the best prognosis.

Only 50 subjects could be interviewed on all four occasions. The subjects estimation of QOL before the stroke did not vary significantly between the interviews nor did reported deterioration, although physical function improved. Less than a third of the subjects reported unchanged or improved QOL after the stroke, most were not disabled. There were 12 improvements, seven were slight. The five remaining subjects gave reasons such as "Felt happier, having been able to slow down", "appreciated life more after the illness" for the improvement in QOL. There were no significant differences between the means of QOL changes for men and women or for those below or above 71 years of age. The socioeconomic group made no difference and those who expressed complaints about the social situation did not evaluate their QOL lower than the others. There was a correlation between changes in QOL and ADL capacity. However, QOL failed to improve with time as ADLs did.

QOL as marked on the study scales seemed to be influenced by physical as well as psychological factors. The psychological influence was investigated with five questions each regarding anxiety and depression with answers graded from 1 = absent to 5 = pronounced. Those subjects who were anxious or depressed during the acute phase showed more QOL deterioration at two years poststroke.

A later study that was part of a prospective long-term follow-up study of life after stroke investigated the extent to which stroke produced long-lasting changes in survivor satisfaction (global as well as domain specific) with life (Viitanen, Fugl-Meyer, Bernspång, & Fugl-Meyer, 1988). There were 62 participants ranging in age from 60 to

60 years at the time of the investigation, 34 were male and 42 were married. The instruments used were the Katz Index, a depression scale by Montgomery and Åsberg, the Mini-Mental State Examination (MMSE), and a structured interview with one item for global and six items for domain specific life satisfaction. A reference group of 88 subjects was used to validate the life satisfaction measure.

Significantly, more stroke survivors, premorbidly, than reference subjects reported that they were very satisfied with life in general. Sixty-one percent of the stroke survivors experienced decreased general and/or domain specific satisfaction with life. Twelve had decreased in four or more aspects, while 14 had decreased in only one aspect. Changes in all the items of domain specific satisfaction were significantly associated with global life satisfaction except for contact with friends, where 85% were as satisfied before as after the stroke. Overall, 42% reported decreased global life satisfaction and 40% of the married stroke survivors reported decreased satisfaction with sexual life. One third of the survivors reported decreases in ADL and leisure satisfaction, and only a few reported decreases in the remaining domains of specific life satisfaction. Changes in global life satisfaction were more pronounced for those who reported to be very satisfied prior to the stroke. The level of motor function was significantly associated with changes in global, leisure and sexual satisfaction. However, a fair proportion of those who reported changes were among the non-impaired stroke survivors. ADL -ability was associated with motor performance. ADL-ability was correlated with changes in global life satisfaction, experienced ADL-satisfaction, and with a decrease in sexual satisfaction. There were no significant correlations with the other items of domain specific life satisfaction. Depression was associated with leisure satisfaction only. Social integration was significantly associated with the degree of experienced global life satisfaction, self-care ADL satisfaction, and with leisure satisfaction.

In this group of five-year stroke survivors, the experienced QOL (global life satisfaction) was decreased by 42% and, counting all items, by 61% mainly global, ADL, leisure and sexual satisfaction. Only small changes occurred for contacts with friends and relatives. The decreases in several aspects of the QOL were dependent upon motor impairment and in turn ADL-disability.

QOL of 46 stroke survivors under 65 years of age in Finland was examined four years post stroke (Niemi, Laaksonen, Kotila, & Waltimo, 1988). Participants were 27 men and 19 women who ranged in age from 17 to 64 years at the time of their stroke. A questionnaire with 58 questions based on literature as well as on clinical experience with stroke patients was designed by the authors. Forty-five questions covered the following domains of quality of life: 1) working conditions, 2) activities at home, 3) family relationships (including close personal relationships and sexual pattern) and, 4) leisure time activities in and outside the home. These survivors were asked to answer the questions as to how things were before the stroke and how the same things were after the stroke. The differences between the prestroke and poststroke answers were used to estimate changes in QOL. The other 13 questions concerned personality, behavioral competence, and relationships with friends and relatives after the stroke. In addition, regular examinations were done at follow-up using the Wechsler Adult Intelligence Scale subtests (arithmetic, similarities, and digit span from the Verbal scale, picture completion and block design from the Performance Scale) and the Wechsler Memory Scale.

At the four year examination 45 of the survivors were living at home, 40 were independent in ADL, and 21 of the 39 who were employed before the stroke had returned to work. Despite the good recovery 38 of the survivors reported deterioration, one restoration, and seven improvement in QOL. Deterioration among the domains ranged from 39% in activities at home to 80% in leisure time activities. The QOL of previously employed survivors that did not return to work differed significantly from those who had returned to work. Stroke survivors with subarachnoid hemorrhages (SAH) had more frequently a restored or improved QOL, and milder deterioration than those with infarctions, which were significant. The same differences also were seen in the individual domains of family relationships and leisure time activities. Stroke survivors with right and left hemisphere lesions had most often and most severely, a deteriorated QOL, and those with a brainstem or no localizable lesion had only mild deterioration. Stroke survivors with right and left hemisphere lesion also had marked deterioration in family relationships and leisure time activities. Older survivors (51-64) had a deteriorated QOL as often as younger survivors; however, the older survivors' deterioration was significantly more severe than that for younger survivors. Age especially affected leisure time activities. Although men reported a more severe deterioration in QOL than women, this was not significant. Only nine survivors had marked residual paresis at four years, and all had a deteriorated QOL, which was more severe than that of those without paresis. The effect of paresis was seen in all four domains. Twenty-three survivors had coordination disturbance and a deteriorated QOL, although the hemiparesis had mostly disappeared. Fifteen had no coordination disturbances but a deteriorated QOL. The difference in severity of the deterioration in QOL between the two groups was significant. This was also seen within each domain. Reduction of intellectual and memory performance was seen as frequently in survivors who had a deteriorated QOL as in those with a restored or improved QOL. However, those who had a restored or improved QOL also had significantly higher mean intelligence and memory quotient scores than those who experienced deterioration in their QOL.

Tendency to depression, difficulties in ambulation, independence in ADL and memory quotient explained 73% of the variance in QOL. Although the survivors had recovered in terms of discharge from the hospital, ADL, and return to work, most (83%) reported deterioration in QOL. The authors conclude that the severity of the strokes and disability had a clear-cut impact on deterioration of QOL, but the most important variable seems to be the survivor's subjective experience of disability and insufficiency.

In a prospective study Åström, Asplund and Åström (1992) assessed the social network, functional ability and dependence, physical and social activities, subjective experiences of ill health, major depression and global life satisfaction of 50 stroke survivors over three years and compared them with a general population of similar age in Sweden. The 50 participants were 71.4 ± 10.8 years of age, 66 % male, 54% married/cohabitant, and first time stroke survivors. The prevalence of self-reported medical problems over the three year follow-up period compared with the national sample showed that hypertension, heart complaints, and diabetes tended to be more frequent in the stroke survivors before the stroke. One year after and throughout the three-year follow-up period, the stroke survivors reported significantly higher frequencies of heart complaints and diabetes than the national sample. Stroke survivors were interviewed about conditions prior to the stroke four to five days post stroke, with follow-up assessments at three months, one year, two years, and three years. Motor deficits and disorientation in the stroke group were done by a stroke unit physician using the Katz Index of ADL functioning and the DSM-III for depression.

The frequency of psychiatric symptoms before the stroke was not significantly different from those in the national sample. After the stroke, there was a significant increase in the proportion of clients who reported dizziness, general tiredness, sleeping problems, anxiety/nervousness, and sadness. Dizziness was as frequent at three years as at three months after the stroke, whereas the other symptoms showed some improvements. At three years, the prevalence of dizziness, anxiety/nervousness, and sadness were still significantly higher than before the stroke and greater than in the general population. The proportion of clients who were dependent on others for ADL was significantly larger at three months than before the stroke with little change over the remainder of the three-year follow-up period. At three months, the proportion of patients with intact function reported a significant decline in IADLs and ambulation. There was no significant improvement for the remainder of the follow-up period.

Prior to the stroke, the proportion of clients engaging in leisure-time activities was not significantly different from the national sample. However, attendance at religious services and sport events, holiday trips, visits to restaurants, and own sport activities, were significantly lower in the stroke survivors prior to the stroke. At three months post stroke there was a reduction in physical leisure activities. At one year, most stroke survivors were again engaged in leisure time activities, which remained essentially unchanged for the remainder of the follow-up period.

Global life satisfaction was markedly reduced, being at its lowest at three months with only 32% of the clients reporting their life as being good. At one year, the proportion increased to 52%, and then remained unchanged. Six of the clients who reported their life as fair at one year reported poor life satisfaction at three years post stroke. All ten clients (20%) who rated their life satisfaction as poor at one year reported poor life satisfaction through the remainder of the follow-up period. The authors indicated that these clients differed from the rest of the stroke survivors in that they were older, had significantly lower IADLs, a more passive leisure time, reported general tiredness and anxiety, lived alone, and had fewer contacts with friends and neighbors than the others.

In comparison with the national sample survivors at three years post stroke had more psychiatric symptoms, lower functional ability, and a reduction in life satisfaction. They maintained contacts with close family over the three year period, whereas contact with other relatives, friends and neighbors declined early after the stroke and remained lower than in the national sample. Between three and twelve months post stroke, the prevalence of major depression decreased, leisure time activities and social contacts were partly resumed, and life satisfaction improved. Once good life satisfaction was restored it was maintained, and poor life satisfaction at one year remained poor for the entire follow-up period.

In this study, the interaction of major depression early after stroke, functional disability, and impaired social network was reported to reduce life satisfaction for the long-term stroke survivor. The authors did not indicate the racial mix of the participants, however, it is safe to assume that the participants were mostly white since the study was done in Sweden. Data on education and income were not provided.

Angeleri, Angeleri, Foschi, Giaquinto, and Nolfe (1993) looked at quality of life in 180 first time stroke survivors who had been discharged for at least one year. Participants were 35 to 93 years of age, 65% male, each had spent an average of 158 days in rehabilitation centers, and the time between stroke and the interview ranged from 12 to 196 months with an average of 37.5 months. On discharge, the stroke survivors had moderate handicaps typical of clients who had impairments. They could walk without help but needed help to look after themselves as measured by the Rankin Scale. ADL functioning was measured by the Northwestern University Disability Scale (NUDS), depression by the Beck Depression Scale, social activity by the Linn Social Dysfunction Rating Scale, and family stress by the Greene Scale.

The control subjects had higher scores for ADL functioning. Thirty percent of the stroke survivors had slight impairment and three subjects had no impairment. There was no gender difference in ADL functioning. The stroke survivors' scores on the Beck indicate moderate to severe depression while the control subjects' mean scores were slightly above the upper limit of norm. The Beck scores of stroke survivors who lived alone indicated that solitude did not worsen the depression. Depression was significantly greater in women than in men. The stroke survivors social activity scores were lower than the control subjects but was not significantly different. A reduction in social activity was greater in women than in men. The stroke survivors had moderate family stress, however, there were no gender differences.

Almost all of the stroke survivors were retired, since the stroke occurred after age 65, only 17% were receiving a disability pension. Twenty-one percent returned to work but not always to the same job, and often after adapting to new conditions. Of those under 65 years of age, twenty-one percent returned to work, women constituted 31% of this group. Most of the stroke survivors were not poor and had homes that were well situated, well furnished, and comfortable, however, 15% had difficult access. The stroke survivors took a variety of drugs platelet antiaggregants was the most frequently used, other medications used were antihypotensives, diuretics, cardiokinetics, and antieplipetics. Three percent took antidepressants, which was well below the percentage of those identified with depression.

Stroke survivors were often criticized for being apathetic, irritable, and self-centered by their cohabitants. Sexual function was reported to be depressed in almost all cases with two percent having increased sex drive, sometimes with sexual deviations.

There was a close correlation between depression, social activity and stress caused to relatives. The authors concluded that their "observation confirm that a high ADL score on hospital discharge indicates a favorable prognosis for the patient's return home and quality of life" (p. 1481). The authors however, did not define, nor did they indicate how they measured quality of life. This study did show that factors that have been associated with QOL were affected in this group of stroke survivors.

The impact of stroke type and lesion location on QOL in 441 stroke survivors in the Netherlands six months poststroke was analyzed (de Haan, Limburg, Van der Meulen, Jacobs, & Aaronson, 1995). QOL was assessed using the Sickness Impact Profile (SIP). The stroke types were divided into three groups, supratentorial (204 subcortical infarctions, 82 lacunar infarctions, and 49 hemorrhages), infratentorial (55 infarctions and 6 hemorrhages), with 45 stroke types unknown or undetermined. The lesions locations were 194 left-sided and 173 right-sided lesions, with lesion laterality undetermined for 74.

No significant differences in QOL were found in subjects with supratentorial subcortical infarcts versus cerebral hemorrhages. Stroke survivors with lacunar infarctions reported significantly less dysfunction in all QOL categories compared to those with subcortical lesions. Stroke survivors with supratentorial lesions reported better functioning overall than those with infratentorial lesions, this difference was not significant. At the subscale level, significant differences were reported, however, in household management and mobility. Mildly impaired QOL was related significantly to younger age, male gender, and infratentorial and lacunar strokes. Serious QOL deterioration was seen in those who had suffered a severe stroke and those with larger supratentorial lesions.

Stroke survivors with overall dysfunction (both physical and psychosocial) tended to be older, have more comorbid conditions than those who experienced primarily psychosocial dysfunction. After adjusting for age, QOL was no longer related to gender, but remained significantly associated with comorbidity, stroke severity, and supratentorial lesion. Stroke survivors reported relatively low levels of emotional distress, and there was no association between emotional dysfunction with lesion location or stroke type.

The role of cognitive impairment in the QOL of stroke survivors was investigated in 129 subjects in the Netherlands (Kwa, Limburg, & de Haan, 1996). Participants were 65 women, 64 men, and their mean age was 63.2 years (SD =14.6). Most had had an ischemic stroke 0.25 to 4 years previously. Cognitive functioning was assessed with the CAMCOG and QOL with a visual analog scale (VAS).

QOL could not be assessed in 32 subjects due to communication problems. In the remaining 97 participants substantial infarct volume, aphasia, impaired motor function, ADL disability, disturbed global functional health, and impaired cognitive function were associated with lower levels of QOL. There was no influence of age, educational level, comorbidity, location of the infarcts, or time since stroke on QOL. The more independent explanatory factors for poorer QOL were disturbed global functional health, and to a lesser extent, larger infarct volume and severity of aphasia.

In a cross-sectional, descriptive correlation study King, (1996) examined overall and domain-specific QOL in long-term stroke survivors to identify the variables that predicted QOL after a stroke. The 86 participants from a Midwestern state ranged in age from 23 to 88 years of age, and were 55% female, 62% married, 78% white, and 69% high school graduates. Four comorbid conditions (a) cardiovascular disease, (b) hypertension, (c) diabetes, and (d) arthritis were found in $\geq$ 20% of the subjects. The following instruments were used: 1) Mini-Mental State Examination ([MMSE] cognitive status), 2) Quality of Life Index-Stroke Version ([QLI] QOL), 3) the Center for Epidemiologic Studies-Depression Scale ([CES-D] depression), 4) the Functional Independence Measure ([FIM] functional status), 5) Social Support in the Elderly Scale ([SSE] social support), and 6) the Hollingshed Four-Factor Index (Socioeconomic status, [SES]).

Predictors of overall QOL were depression, perceived social support, and functional status, which explained 38% of the variance in QOL. Socioeconomic QOL was predicted by SES, cardiovascular disease, social support, and age. The greater the depression, less social support, lower functional status, presence of cardiovascular disease, younger age, and lower SES the lower the overall and/or domain QOL. Arthritis, diabetes, hypertension, motor impairment, and aphasia were not predictors of QOL.

Cross-culturally, Yoon (1997) examined factors that affected quality of life of 119 stroke survivors, 60 years of age and older, in Korea. The model used family support, hardiness, economic status, and physical functioning as independent variables and QOL as the dependent variable. The participants mean age was 68.8 years (SD = 11.3), 50.4% men, 73% had a living spouse, 26.9% were widowed, separated, or divorced, and the majority was retired (only 21.8% were working prior to the stroke). Instruments used were the SIP (QOL), Barthel Index (physical functioning), a composite of personality factors termed "hardiness", and a Family Support Scale (emotional family support). Other measures of family support were financial support and physical care. Economic status was measured by the amount of monthly income.

Physical functioning and physical care by the family had a significant effect on QOL. Hardiness and economic status had no significant effect on QOL. Hardiness was found to be negatively associated with financial support and physical care.

In a cross-sectional study done one-year post stroke in Norway, the subjective well-being of stroke survivors was compared with that of a reference group, and the effect of impairments and disabilities upon well-being was explored (Wyller, Sveen, Sødring, Pettersen, & Bautz-Holter, 1997). The participants were 60 stroke survivors who ranged in age from 55 to 89 years and 34 were men. The reference group consisted of 419 community dwelling subjects ranging in age 67 to 97 years and 38 % were men.

The instruments used were 1) the General Health Questionnaire ([GHQ], subjective well being), 2) Barthel Index (ADL), 3) Frenchay Activities Index ([FAI], social activities and IADL), 4) Sødring Motor Evaluation of Stroke Patients ([SMES], motor function), 5) MMSE and the Cerebral Stroke and other Brain Damage ([ASB], cognitive functioning).

Gender alone explained 9.5% of the variance in subjective well-being. Introduction of age into the model did not increase the explained variance. A model with gender and arm motor function explained 47.9% of the variance in subjective well-being.

Duncan et al, (1997) assessed the health status of 304 persons with mild stroke, and compared them with 184 persons with TIA and 654 persons without history of stroke/TIA but at elevated risk for stroke (asymptomatic group). Participants were from several states in the United States of America, mostly white, more than half were males and mean age 65 years. The three groups were dissimilar in three areas: 1) the asymptomatic group was older and included a relatively higher percentage of whites; 2) individuals with stroke were less likely to be employed; and 3) the TIA group had relatively less social support.

The instruments used were Barthel Index, CES-D, the MOS-36 and the Time trade-off (TTO) to measure HRQOL. The results showed that all groups were highly independent in ADLs. The stroke group was significantly more impaired than the asymptomatic group in every dimension of the MOS-36 except pain. Those with stroke and TIA had higher depression ratings than the asymptomatic group. There was a strong correlation of the CES-D scores and the mental health and emotional role function of the MOS-36 scores. HRQOL was lower for individuals with stroke. The TIA and asymptomatic group did not differ in HRQOL. Overall, the Barthel Index and history of stroke were the strongest and most consistent predictors of health status.

Inderedavik, Bakke, Slørdahl, Rokseth, and Håheim (1998) tested the hypothesis that treatment of patients in an acute stroke unit improved different aspects of long-term QOL compared with those treated in a general ward in Norway. Participants included 37 stroke survivors from the stroke unit and 25 from the general wards. Instruments used were the Barthel Index, the FAI, and the Nottingham Health Profile (NHP) and the VAS for QOL.

The results showed that significant differences in favor of the stroke unit were found in the dimensions of energy, emotional reaction, social isolation, physical mobility and sleep on the NHP with no difference in pain. Those in the stroke unit group also had significantly higher scores on the FAI. The stroke unit group QOL as measured by the VAS was significantly better than the general ward group.

In this study, the three objectives were to study subjective well-being (SWB) as a latent variable, to assess reliability of the items related to the latent variable, and to study variables explaining SWB in a large population-based sample of stroke survivors and stroke-free individuals in Norway (Wyller, Holmen, Laake & Laake, 1998). There were 1417 stroke survivors mean age 71.6 years and 48% were men. The reference group consisted of 1439 individuals with the same age distribution as the stroke survivors. The items used to assess SWB were satisfaction, strength, calmness and cheerfulness. The explanatory variables were age, gender, and several indicators of general and mental health, functional capacity, social network, and morbidity.

The authors reported that stroke survivors had significantly lower SWB than control subjects of similar age. In stroke survivors and non-stroke subjects, high SWB was mainly explained by female gender, older age, good general and mental health, and a firm social network.

Forty-seven stroke survivors were assessed in their homes three years after discharge and interviewed to explore the relationship among subject characteristics, impairments, disabilities and psychological well-being (Löfgren, Gustafson, & Nyberg, 1999). The instruments used were the Philadelphia Geriatric Center Morale Scale ([PGCMS], psychological well-being), the Montgomery-Asberg Depression Rating Scale ([MADRS], depression), the Katz Index, the MMSE, and the Brunnström-Fugl-Meyer Scale (Motor function, postural stability, sensory function, and range of motion).

More than half (64%) of the stroke survivors had high or middle-range scores on the PGCMS indicating psychological well-being. They seemed free from agitation and satisfied with their social interaction but were less content with their aging process. Depression was closely linked with low psychological well-being. However, not all stroke survivors with low scores were depressed. Social situation, impairments and disabilities did not appear to influence the stroke survivors' psychological well-being.

Kim, Warren, Madill and Hadley (1999) used a cross-sectional design to identify those factor that influence QOL of 50 stroke survivors in Canada one to three years post discharge. The objectives of the study were: 1) to describe the overall QOL of community-based stroke survivors one to three years after discharge from a local rehabilitation hospital; 2) to examine the relationship between QOL and possible predictors including functional status in terms of ADL, IADL, perceived social support, perceived health status, and post-stroke depression; 3) to examine the influence of eight possible intervening sociodemographic and stroke-related variables on QOL: age, gender, marital status, education, income, living arrangements, stroke type, and localization of lesions; and 4) to determine which combination of all the variables measured best predicted QOL for long-term survivors of stroke.

The instruments used were the QLI- Stroke version (QOL), the FIM (functional status), the FAI (IADL), Social Support Inventory for Stroke Survivors ([SSIPAD], perceived social support), CES-D (depression), and a single age-referenced health question for perceived health status. The participants ranged in age from 63 to 86 years of age, 58% male, 68% married and 66% lived with their spouse or another family member. The majority of participants (74%) had incomes from $20,000 to $40,000 per year or more, and the majority (56%) had graduated from high school or had some post secondary education. The location of the lesion was right sided in the majority of the participants (55%) and the stroke type was infarcts in 74%.

The FIM, FAI, Total quality SSIPAD, CES-D, and perceived health status scores were all positively correlated with QOL. Marital status and income were two intervening variables that were significantly associated with overall QOL. Age, gender, education, living arrangements, stroke type, and location of lesions did not correlate significantly with QOL. Depression, marital status, quality of social support, and IADL were significant predictors of QOL. Together they explained 60.1% of the variance in QOL Depression, which was entered into the equation first accounted for 32% of the variance in QOL. When the remaining variables were entered and the effects of depression removed marital status accounted for 15%, social support 9%, and IADL 6% respectively of the variance of QOL. The overall QOL score indicated moderate QOL. In addition, a subsample of 42% reported dissatisfaction or slight satisfaction with leisure time activities.

In a preliminary cross-sectional study the influence of time on the QOL of chronic hemiplegic stroke survivors living at home was evaluated (Bethoux, Calmels, & Gautheron, 1999). The participants were divided into two groups; based on time from discharge to time of assessment, Group 1 less than six months and Group 2 more than six months from discharge. There were 28 participants in Group 1 ranging in age from 51 to 75 years and 68% males. Group 2 had 17 participants ranging in age from 43 to 69 years and 71% males.

The instruments used were the FIM and the Reintegration to Normal Living Index ([RNLI], QOL). No significant difference was found between Group 1 and Group 2 with regard to age, gender, etiology of stroke, side of hemiplegia, aphasia, and use of home services. There was no significant difference in FIM scores between the two groups. There was no significant difference in RNLI total and daily functioning scores between the groups, however, the RNLI perception of self scores were significantly lower in Group 2. Analysis of the RNLI profile for the two groups revealed a higher level of satisfaction for indoor mobility, self-care needs, personal relationships and the company of others and a lower level of satisfaction for outdoor mobility, activities and roles within the family. Satisfaction for indoor mobility, self-care needs, personal relationships, and the handling of life events was significantly lower in Group 2. These findings suggest that QOL may deteriorate over time even when disability level is unchanged.

HRQOL was compared among long-term stroke survivor with age and sex matched control subjects and with a national population as determined by the SF-36 questionnaire in New Zealand (Hackett, Duncan, Anderson, Broad, & Bonita, 2000). There were 639 stroke survivors, 117 had experienced a second stroke; and 310 control subjects, 14 controls had a history of stroke since 1992. The age ranges were 25 to 96 for the stroke survivors, and 28 to 98 for the controls; and 51% and 54% females respectively.. Stroke survivors were more likely to be taking antihypertensive medications than the controls (54% versus 35% respectively), which was significant, however, there was no difference in the proportion of current smokers. The interviews were done mainly by telephone with information provided by proxy for some participants in both groups.

The results showed that the total crude mean score for the stroke survivors were significantly lower than for the controls across all domains, with the greatest difference in physical functioning and the smallest difference in bodily pain. Lower scores were found for women, as age increased, and for those more dependent. After standardization for age and gender compared with controls the stroke survivors had significantly lower scores in physical functioning (PF), role limitation due to physical problems (RP), general health (GH), and role limitations due to emotional problems (RE), but no differences were found in bodily pain (BP), vitality (VT), social functioning (SF) and mental health (MH). The stroke survivors scores were lower compared with New Zealand norms, after standardization for age and gender, in PF, GH, VT, and SF, but no differences were found in the other domains. This study showed that HRQOL was generally good for those six year stroke survivors. This study included stroke survivors who were residents in institutions, severely disabled, or had communication problems.

Carod-Artal, Egido, González, and de Seijas (2000) examined global and domain-specific QOL in stroke survivors who were treated in a stroke unit in Madrid, Spain. The participants were 41 women and 49 men who ranged in age from 32 to 90 years, 79 had ischemic strokes and 11 had hemorrhagic strokes, all participants were white and family support seemed to be strong since 87.8% lived with a spouse or relative. Instruments used were Barthel Index (BI), Scandinavian Stroke Scale ([SSS], neurological impairment), the Rankin Scale, the FAI, the Hamilton Rating Scale for Depression, the Medical Outcomes Short Form Health Survey (SF-36) and the Sickness Impact Profile (SIP).

Thirty-one percent of the stroke survivors needed walking assistance, cane or wheelchair for ambulation 12 months after the stroke, and 36 had fallen at home, in the bathroom, or in the street. However, there was no significant correlation between falls and dimensions of the SIP. Fifty–two percent of the subjects were independent in ADL at one year, while only 32% were independent at stroke onset. At one year, only 11% were severely disabled versus 40% at discharge. BI scores in women were significantly lower than for men at both onset and one-year follow-up, with no difference based on age. The SSS total score at one year was 50.9. Subjects with lacunar and atherothrombotic stroke subtypes had significantly lower SSS scores. Women also had lower SSS scores than men. The mean Rankin Scale score was one point lower at one-year follow-up than at discharge. There was no significant difference in the global FAI scores based on age or gender. Men scored significantly better in the subscales hobby/work and social activities, but there was no difference based on gender in the domestic work category. Subjects with severe disability (50%) had diminished scores in the three FAI subscales and social activities were significantly decreased. A third of the subjects had depressive symptoms at discharge, 67% were depressed at one year with 37.7% scoring in the range of major depression. However, only 13.3% were receiving antidepressant, and 24.4% were receiving sedatives at one year. Depression was significantly higher in women (78%) than in men (57%), as was severity and time of illness. There was no correlation between stroke laterality, stroke subtype, marital status, nor educational level and depression. Status as a housewife and inability to work because of a poststroke disability were significantly correlated with depression. Poststroke depression was therefore highly prevalent (37.7%) and associated with female gender, status as a housewife, handicap that affected ability to work and diminished social activity one year after.

The mean scores on the SF-36 subscales were decreased 40% from the theoretical values of reference (100). QOL as measured by the SF-36 was significantly lower in women, the main differences were observed in physical functioning, mental health, emotional role and vitality. Women perceived lower QOL in all dimension of the SF-36. Bodily pain was the only subscale that decreased with age. Low QOL was significantly correlated with depression and severe disability. Social function was affected more in disabled than in depressed subjects, while vitality decreased slightly more in subjects with depression. The SF-36 social function was correlated with the FAI social activities category.

The mean SIP score after one year was 24.3; mean physical dimension score was 21.3 and the psychosocial dimension 27.5. The categories of home management (42.6), emotional activity (31.2), and recreation (32.1) were the most altered. The variables related to deterioration of QOL as evaluated by the SIP were female gender, cerebral anterior circulation infarction, cardioembolic or atherothrombotic stroke type, depression, disability, and sociodemographic variables such as work-related disability and status as a housewife. Those stroke survivors who were independent in ADL at one year also were affected on the psychosocial domain (21.24). Stroke survivors who were not depressed as measured by the Hamilton Scale scored 14 in this category, while depressed subjects scored 50.1. There was a strong correlation between the SF-36 physical functioning and SIP body movement, SIP transfers, SIP home management, SIP physical dimension, and total SIP, and between the SF-36 mental health and the SIP emotional role, psychosocial dimension and the total SIP.

The good recovery of the stroke survivors was shown by the ADL, social activities and return to work. However, significant deleterious effects persisted in QOL of those independent in ADL who did not achieve the level of function they enjoyed before the stroke as shown by the result of the psychosocial dimension of SIP and all the subscales for the SF36. Depression and disability were the strongest predictors of overall psychosocial and physical QOL measured with the SF-36 and the SIP. Poststroke disability was a stronger predictor of low QOL than poststroke depression. Stroke survivors with sever/moderate disability had lower QOL than depressed subjects. Isolation and diminished social activities were the result of physical disability more than depression. Older age or lower educational level was not correlated with low QOL although there was a weak relationship with increasing educational level. Comorbid conditions such as diabetes, hypertension, or other vascular risk factors did not decrease global QOL. Social support was an important predictor of depression. Social activities as measured by the SF-36 were lower in women. Women had a lower Barthel Index score both on admission and at one year. Women also had a lower SSS score at one year and a lower QOL as assessed by the SIP and SF-36.

Kauhanen et. al. (2000) studied 85 stroke survivors, 36 women, and 49 men; ranging in age 9 to 82 years, mean 65, (SD = 12.5). Neurologic impairment was assessed by the Scandinavian Stroke Scale (SSS), ADLs using the Barthel Index (BI), degree of handicap by the Rankin scale, and intellectual deterioration by the Mini-Mental State Examination (MMSE). Depression was evaluated by a psychiatric examination at three months and 12 months using the Diagnosis and Statistical Manual of Mental Disorders, Revised Third Edition (DSM-III-R) and quality of life (QOL) was measured by the Finnish version of the Rand 36-Item Health Survey1.0 (Rand-36). The Rand-36 comprises eight dimension: physical functioning, role limitations due to physical problems (role limitations - physical), mental health, role limitations due to emotional problems (role limitations – emotional), vitality, social functioning, bodily pain, and general health. The authors found that all dimension of QOL, except mental health were low in patients with mild to moderate stroke at three months poststroke. The domains physical functioning and role limitations - physical improved at 12 months. Depression was reported to be significantly correlated, with various dimensions of QOL at three months and 12 months poststroke. At 12 months, men had a poorer outcome as measured by role limitations – physical (p = .039) and vitality (p = .019). Being married correlated significantly with low scores on the role limitations – physical (p = .043), vitality (p = .005), and role limitations – emotional (p =.01) one year poststroke. Stepwise logistic regression analysis showed that depression and being married were the most important determinant of impaired role limitations – physical, and being married, depressed and old impaired vitality. They also reported that although neurologic impairment and functional ability improved at 12 months QOL did not.

Badke (2000) used the Health and Activities Limitation Index (HALex) to look at the health status of community dwelling stroke survivors. The research questions were: 1) what environmental, psychological, and physical variables are associated with HRQOL after stroke?. and 2) what demographic variables are associated reliably with differences among stroke survivors in their HRQOL? A secondary analysis of a large, cross-sectional health interview survey, the Supplement on Disability of the 1994 National Health Interview Survey (NHIS-D) was done.

The sample consisted of 520 stroke survivors and 12,442 controls. The mean age 68.1 (SD = 13.2) for the stroke survivors, and 67.6 (SD = 13.6) for the controls; more than half were females (54.5% stroke and 55.4% controls). The differences between the control and stroke groups on other demographic variables were: 1) the control group had a higher percentage of white (86.1% control versus 80.1% stroke), 2) family heads with more years of schooling (42% control versus 32.2% stroke) living alone (25.8% control versus 34.4% stroke), and income greater than $20,000 (67.7% control versus 37.6% stroke).

Depression or anxiety was reported by 24% of the stroke group compared to 7.3% of the controls. Stroke survivors reported being in poor to fair perceived general health compared to 23.9% of the controls. The stroke group was also significantly more impaired in physical ADLs (57.2%) compared to 14.6% of the control group. Individuals with stroke were 4.14 (C. I. 3.15, 5.44) times more likely to report being unable to perform their major activity or being limited in ADLs and IADLs than the control group. Stroke survivors were 2.35 (C. I. 1.84, 2.29) times more likely to report perceived health as fair or poor versus excellent, very good or good than those without stroke. Individuals who reported comorbid conditions, cognitive difficulties, and those with speech impairments had more difficulties with ADLs/IADLs, and those reporting difficulty coping with day-to-day stresses were 3.90 (C. I. 1.80, 8.43) more likely to report poor health. Older age did not predict HRQOL.

Summary

The relationship between age, gender, ADL functioning, social support, time, depression, upper extremity strength, comorbidity, type and location of lesion, and socioeconomic status and QOL were examined in the studies reviewed. Some factors were reported to be significant predictors of QOL in some studies but not in others. However, ADL functioning emerged as a predictor of QOL in many of the studies.

The relationship among age and QOL was mixed. Four studies reported that younger age was associated with lower overall and/or domain quality of life (Ahlsiö et al., 1984; de Haan et al., 1995; King, 1996; Niemi et al., 1988). Another study (Wyller et al., 1998) reported that older age was related to higher subjective well-being. And Kauhanen et al. (2000) found vitality was lower in those over 65 years of age. No association between age and QOL was found in four of the studies (Badke, 2000; Carod-Artal, et al., 2000; Löfgren et al., 1999; Kwa et al., 1996).

Wyller et al. (1997) found that male gender and upper arm function were the only predictors of subjective well-being (SWB). Females reported higher levels of SWB/QOL in two studies (Badke, 2000; Wyller et al., 1998), while in another study men reported mildly impaired QOL (de Haan et al., 1995). Another study found a weak association with gender and psychological well-being (Löfgren et al., 1999). Niemi et al., (1988) reported that men had a more severe deterioration in QOL than women did; however, this was not significant. No association was found between gender and QOL/SWB in two studies (Ahlsiö et al., 1984; Kwa et al., 1996).

ADL functioning was examined in 13 of the studies. The level of ADL-ability/disability was associated with QOL/SWB, the greater the ADL-ability the better the QOL/SWB and the greater the ADL-disability the lower the QOL/SWB. In two studies, the authors indicated that the stroke survivors responses to their disability was more important than the physical disability itself (Carod-Artal et al., 2000; Lawrence & Chrisite, 1979). In only one study was ADL functioning not associated with QOL/Psychological well-being (Wyller et al., 1998).

Depression was associated with leisure satisfaction but not overall QOL in one study (Viitanen et al., 1988); however, depression was a predictor of QOL/Life

Satisfaction/Psychological well-being in six studies. It was significantly greater in females than males in two of the studies (Angeleri et al., 1993;Carod-Artal et al., 2000).

Social network/social support was only measured in six studies. In one study, social support was not a predictor of QOL but was an important predictor of depression (Carod-Artal et al., 2000), which was a significant predictor of QOL. Negative social support was reported to decrease sexual functioning (Angeleri et al., 1993). Interestingly, hardiness was negatively associated with financial support and physical care in one study (Yoon, 1997). In the other four studies, social network or perceived social support was a predictor of QOL. The lower the level of social support or an impaired social network the lower the level of SWB/QOL; whereas the firmer the social network and higher the level of social support the higher the level of SWB/QOL.

King, (1996) found that socioeconomic QOL was predicted by socioeconomic status (SES) but there was no association with overall QOL. However, in two other studies SES made no difference in the QOL (Ahlsiö et al., 1984; Yoon, 1997). Lawrence and Christie, (1979) reported that six out of eight non-English speaking stroke survivors ceased work prematurely. SES was not assessed in the other studies. Most of the participants in the studies were retired or receiving disability pensions, living situations were reported as comfortable.

The effect of time on QOL of stroke survivors were mixed. In one study a pattern of decreasing QOL, which reached a low at three months poststroke, followed by a significant rise one year poststroke, and remained unchanged over the next three years was found (Åström et al., 1992). Bethoux et al. (1999) found that the longer the time since discharge the lower the QOL. Quality of life was reported to not improve with time in two studies (Ahlsiö et al., 1984; Kauhanen et al., 2000).

Stroke survivors' QOL was reported to be lower than community groups that were comparable in age and gender in three studies (Åström et al., 1992;Duncan et al., 1997; Wyller et al., 1998). Overall, stroke survivors experienced changes in their QOL/Life Satisfaction/Psychological well-being/SWB. The authors of one study reported that the QOL of the majority of the stroke survivors was relatively good (Hackett et al., 2000).

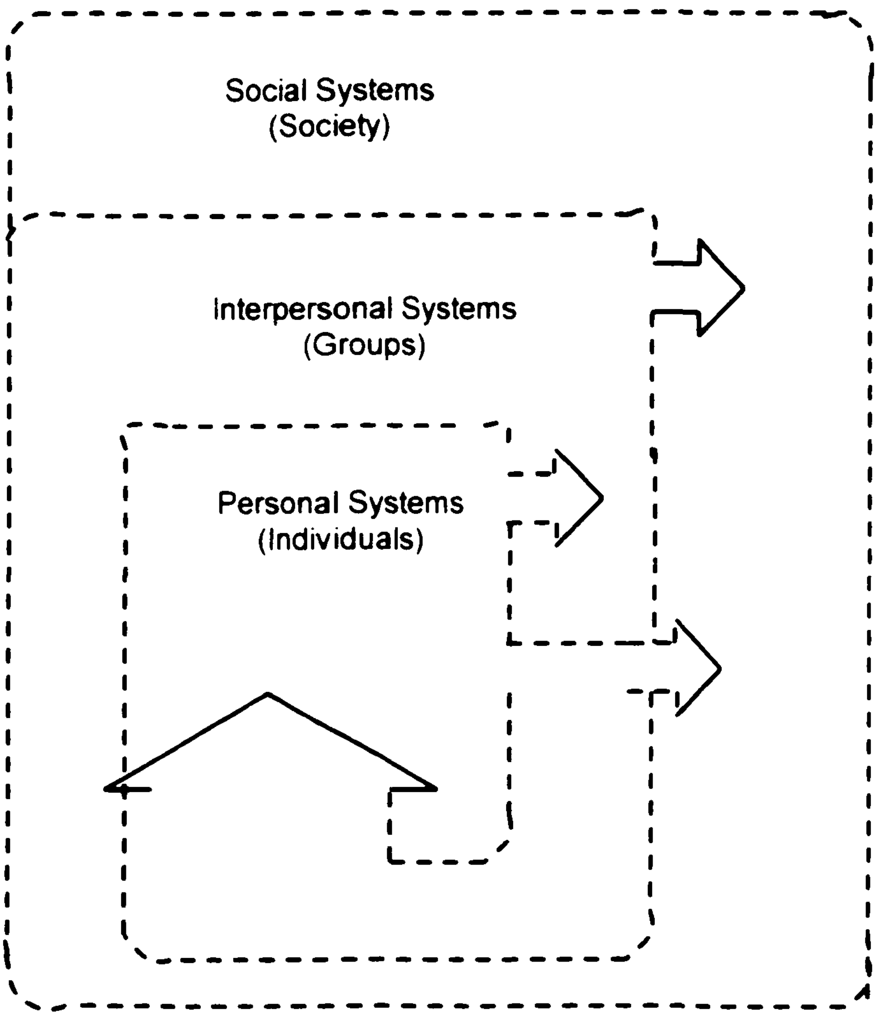
Other predictors of changes in QOL were comorbidity, type of lesion, location of lesion, place of treatment and cognitive functioning. In one study cardiovascular diseases was associated with QOL (Badke, 2000); however, in another study comorbidity was not associated with QOL (Carod-Artal et al., 2000). In one study, sexual satisfaction was reported to be decreased as a result of negative social support (Angeleri et al., 1993) the other studies did not assess sexual functioning. The type of lesion but not location was reported to be a predictor of QOL in one study (de Haan, et al., 1995), but in another study the lesion location was associated with deterioration in QOL (Niemi et al., 1988). Stroke survivors treated in a stroke unit had better QOL than those treated in a general unit (Indredavik et al., 1998). Impaired cognitive functioning was reported to be associated with lower QOL (Kwa et al., 1996).

The major limitations in assessing predictors of QOL poststroke in the reported studies are the lack of consensus in the definition of QOL and the variation of instruments used to measure it. One study did not define QOL nor indicated how it was measured, but reported that ADL was a significant predictor of QOL. The instruments used to measures QOL were Visual Analog Scales, Short Form-36, Sickness Impact Profile, the stroke survivors attitudes about the future, bar graphs, structured interview questions related to life satisfaction, General Health Questionnaire, Nottingham Health Profile, Philadelphia Geriatric Center Morale Scale, Quality of Life Index -Stroke version, Health and Activities Limitation Index, and Reintegration to Normal Living Index. None of the studies used a stroke specific QOL measure to assess QOL.

The majority of the quality of life of stroke survivors studies were done in Europe, only four were done in the United States and one in Canada. As a result, the results may not be representative of the American culture and may therefore not be generalizable to American stroke survivors. In the European studies, there was no mention of the ethnicity of the participants. In the American studies, African Americans represented 8% (Duncan et al., 1997), 12% (King, 1995), 18% (Badke, 2000) and ethnicity was not reported by Bethoux et al. (1999).

Despite considerable research, there is little consistency in conceptualizations of QOL, type of measurement used, and a low percentage of African American participants. African Americans have a 2-3 times higher risk for stroke compared with Caucasians (AHA, 2002) and should therefore be included in studies of stroke survivors quality of life. The majority of the studies were done by physicians. None of the studies reviewed used a nursing framework. In order to address these limitations this study is designed to develop and test a middle range theory of health-related quality of life in stroke survivors. The study is derived from a nursing perspective, samples in a predominantly African-American inner city population, and uses a stroke specific quality of life instrument. King's (1981) conceptual framework provides building blocks to develop and test this middle range theory of HRQOL of stroke survivors based on proposed theoretical relationships derived from the framework and empirical predictors of QOL of stroke survivors (See Figure 1).

Figure 1. King's Conceptual Framework for Nursing



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CONCEPTUAL FRAMEWORK

Conceptual frameworks by definition are broad, abstract theoretical systems, which are not directly testable. However, they do provide direction from which to develop middle-range theories that can be directly tested. The concepts, which are derived from the conceptual framework, provide the building blocks for the development of the middle-range theory. Middle-range theories according to Meleis (1997) "consider a limited number of variables, have a particular substantive focus, focus on a limited aspect of a relationship, are more susceptible to empirical testing, and can be consolidated into more wide-ranging theories" (p. 260). Middle-range theories can be constructed by means of several different theory development strategies (Meleis, 1997; Walker & Avant, 1995). The process of theoretical substruction as explicated by Dulock and Holzhemer (1991) was used in this work to move from the highest level of abstraction (the theoretical constructs) to the lowest level of abstraction (the scores of the empirical indicators). King's Interacting Systems Framework for nursing provided the basis for the development of the conceptualization of health-related quality of life of stroke survivors. King's conceptual framework is based on the following assumptions.

1. the focus of nursing is the care of human beings
2. human beings are open systems interacting with their environments
3. the goal of nursing is concern for the health of individuals and the health care of groups (King, 1971, p. 10).

At the highest level of abstraction are the three theoretical constructs of King's dynamic interacting systems: the social system, the interpersonal system, and the personal system. The next level of abstraction is the theoretical concepts, which are relevant for understanding the constructs. The subconcepts, which are derived from the concepts, are less abstract but still not measurable. The empirical indicators are operationalization of the subconcepts and are more concrete and measurable. Finally, the measure scores indicate the level of measurement.

King's (1981) borrowed many of her concepts from other disciplines and redefined them. They serve as the building blocks of her framework and identify relevant knowledge for understanding the system.

The focus of the conceptual framework is individuals or personal systems, interacting with others in a variety of social systems (King, 1981, p. 19). The concepts of perception, self, growth and development, body image, time and space are relevant for understanding of individuals as personal systems. Individuals are characterized as social, rational and sentient beings who are able to perceive, think, feel, to choose between alternate courses of action, to set goals, to select the means to achieve goals, and to make decisions (p. 19).

Individuals interact with others in multiple settings and situations to form interpersonal systems. Interpersonal systems vary from dyads to larger groups. The concepts identified by King (1981) as relevant for understanding two or more persons interacting are role, interaction, communication, transaction, and stress. The greater the number of persons interacting the greater the complexity of the interaction.

Social systems unlike interpersonal systems are groups that share common interest and goals (King, 1981). The family, religious systems, educational systems, work systems, and peer groups are social systems. The systems provide the rules of behavior, modes of interaction, and define social relationships that influence individuals as they grow and develop from childhood to adulthood. Concepts that King identified as important in understanding social systems are organization, power, authority, status, and decision-making.

Interaction is essential for developing relationships is an axiom that shows how the constructs are related. The arrows linking all three of the constructs indicate the interactions that go on among them. The vertical arrows indicate the level of abstraction and horizontal arrows indicate the relationship among the constructs, concepts and subconcepts (Figure 2).

The concepts of perception, interaction, self, and health are defined according to King (1981). Derivation of the concepts of perceptual integrity, social support, perception of level of disability, and health-related quality of life from the foregoing concepts using the strategy of substruction will be discussed. Definitions of these concepts and the relationship among them constitute the conceptualization of health-related quality of life for stroke survivors. Testing of the middle-range theory of quality of life for stroke survivors will provide indirect testing of the propositions of King's conceptual system from which it was derived. Empirical support for this middle-range theory will provide some verification of the conceptual system.

Perception

King (1981) defines perception as "a process of organizing, interpreting, and transforming information from sense data and memory. It is a process of human transactions with environment. It gives meaning to one's experience, represents one's image of reality, and influence behavior" (p. 24). Perception is universal, subjective, personal, and selective for each person. The individual's perception of others and objects in the environment provide experiences from which they form views of the world. Perception is selective in that each individual determines what stimuli are permitted to enter from the environment. The experiences of each person vary depending on spatial-temporal relationships, the integrity of the nervous system, level of development, and the context in which perceptions are experienced. Factors that serve to organize one's perception are awareness of past events, values, and needs. Role, status in the family, in the world of work, and in recreation influences the individual's perceptions. Because perceptions are based on the individual's background of experiences, they are uniquely personal.

An internally altered nervous system, sensory stimulation, overload, or deprivation, and some personality factors may alter perceptions. The concept of perception is essential to understanding persons as systems and the influence perception has on human interaction. Because of the influence perception has on human interactions it is a process of human transactions with the environment.

Perception is defined as the act of perceiving or of receiving impressions by the senses, that act or process of the mind, which makes known an external object. Perceptual is defined as involving perception (Houghton Mifflin's College Dictionary, 1986, p. 872). Integrity is the state of being unimpaired (Houghton Mifflin's College Dictionary, p. 634). Perceptual integrity is therefore the state of unimpaired functioning of bodily systems or organs that are involved in sensing or perceiving the world.

Stroke sequelae may result in impairments of a number of body system that could impair perception which may include: neglect of involved extremities, homonymous hemianopia, loss of depth perception, double vision, nystagmus, dysphasia, dysgraphia, aphasia, perseveration, confusion, shortened attention span, loss of mental acuity, short term memory loss, impulsivity, problems conceptualizing and generalizing (Schnell, 1997). These impairments can cause major changes in the individual. Stroke survivors also suffer from depression with reported rates varying from 22 to 53 percent (Aström. 1996; Aström, Adolfson, & Asplund, 1993; Herrmann, Black, Lawrence, Szekely, & Szalai, 1998, Kauhanen , 1999; Pohjasvaara et al., 1998; Swartzman, Gibson, & Armstrong, 1998). Depression post stroke was also associated with generalized anxiety disorder (GAD), abnormal illness behavior (AIB), and cognitive impairment in the domains of memory, nonverbal problem solving, attention and psychomotor speed being the most likely to be affected (Aström; Clarke & Smith, 1998).

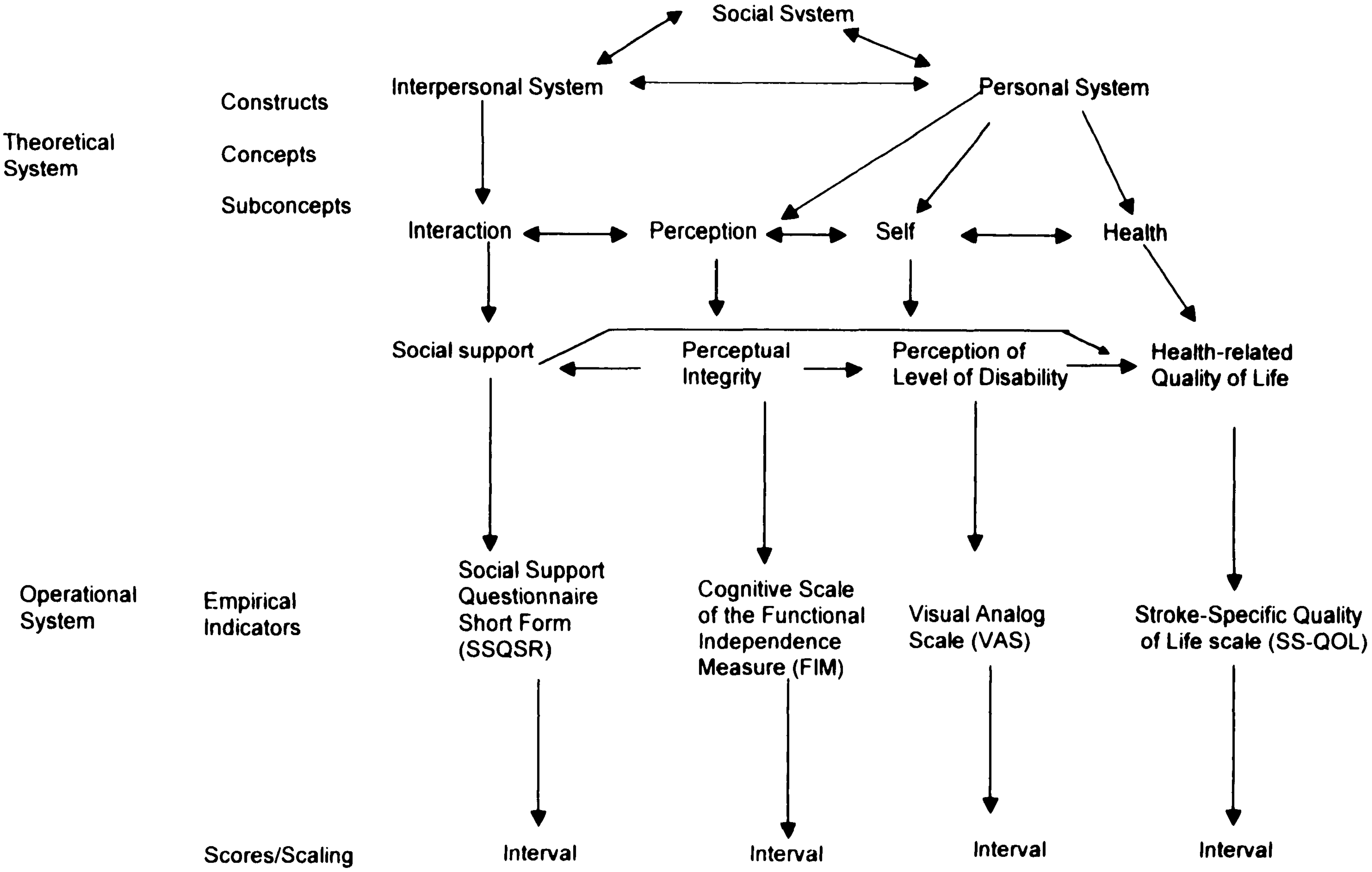


Figure 2.
Theoretical Substruction of social support, perceptual integrity, perception of level of disability, health-related quality of life as derived from King's (1981) conceptual framework

In a review of the literature Swartzman, Gibson, and Armstrong (1998) identified depression, anxiety, emotional lability and disinhibition, catastrophic reaction and aggression, and indifference reactions as behavioral changes that occur poststroke. Pound, Gompertz, and Ebrahim (1998) found that stroke survivors reported feelings of unhappiness, difficulty talking (especially with strangers) poor memory and confusion.

King (1981) concurs that an internally altered nervous system and illness may alter perceptions (p. 25). Research has shown that impairments experienced by the stroke survivor, can change the integrity of the nervous system and may cause personality changes. These changes alter the stroke survivor's perceptions; therefore, the subconcept of perceptual integrity can be logically derived from perception. Perceptual integrity is operationally defined as the individual's assessment of their cognitive functioning as measured by the Functional Independence Measure ([FIM], UDS Data Management Service, SUNY Buffalo, 1993). Items on the cognitive subscales include comprehension, expression, social interaction, problem solving and memory, the empirical indicators of perceptual integrity. Scores are at the level of interval measurement.

Interaction

Interaction in King's (1981) conceptual framework includes both process and content. The process of human interaction as used by King was derived from social psychology. The process model includes perception, judgment, and actions of individuals; as well as reaction, interaction, and transaction between individuals. Interactions occur between two or more persons. Each interaction involves both verbal and nonverbal communication that is characterized by values and is goal directed. Individuals bring personal knowledge, needs, goals, expectations, perceptions, and experiences that influence the interaction. King identified interaction as being universal and reciprocal. She states, "a concept of perception is fundamental in all human interaction" (p. 61). Two other concepts that were also identified as being fundamental to interaction are communication (the informational component) and transaction (the valuational component). Communication is defined as information exchange. Interaction also involves the exchange of material goods and/or services.

Interaction is essential to the development of relationships. The result of interaction in relationships is growth, change, and personal development. Interactions may therefore have either a positive or a negative influence on health.

Social support is conceptualized as human interaction based on King's (1981) view of interaction. It is a multidimensional construct derived from stress and coping theory. There is no single definition of social support to date. Cobb (1976) defined social support as information leading one to believe that he or she is cared for or loved, esteemed, or valued, and part of a network of communication and mutual aid. Weiss (1974) proposed that social support included the provision of attachment, social integration, nurturance, and obtaining of guidance through social relationships. Kahn (1979) defined social support as interpersonal transactions that include one or more of the following: the expression of positive affect, affirmation of behaviors, and the giving of symbolic or material aid to another. House (1981) defined social support as interpersonal transactions involving emotional concern, information, appraisal, or instrumental aid. Cohen and Syme (1985) attempted to integrate multiple perspectives, definitions, and outcomes, and broadly defined social support as the resources provided by other persons, this definition allows for the possibility that support may have negative as well as positive effects on health and well-being. Diamond and Jones (1983) in an attempt to integrate the multiple definitions into a broad theoretical definition of social support identified four points on which various definitions converge: (1) communication of positive affect, (2) a sense of social integration, (3) reciprocity of directedness as a factor in the continuance of support and satisfaction in interaction, and (4) the provision of tangible aid.

Although there is some diversity in the definitions of social support, it is conceptualized as a component of social interaction with family, friends, neighbors, and others with whom one has personal contact. Consistent with King's (1981) view of the content and character of interaction are the elements of (a) reciprocity, (b) exchange of aid and communication, and (c) mutuality. The quality of interactions influences health; therefore, the quality of social support as a component of interaction can also be expected to influence health. Social support as a human environment interaction based on King's concept of interaction has been used by other researchers (Frey, 1987; Fries, 1999) as well.

For this study, social support is operationally defined as the individual's assessment of their perceived social support and satisfaction with it. The empirical indicators will be the scores on the Social Support Questionnaire Short Form ([SSQSR], Sarason, Sarason, Shearin, & Pierce 1987). The level of measurement is interval.

Self

Self is dynamic with values and beliefs that help one to maintain balance in life. Self is perceived in relation to others and objects in the environment. Interactions with others give one a sense of self. Positive interactions enhance self while negative interactions diminish self. Each person is unique in genetic inheritance, experiences, and perceptions of the external world. Individuals acquire values, needs, and goals through growth and development that give them an awareness of personal separateness while recognizing the influence of others and their reactions to the self. Self is goal-oriented with activities directed towards personal fulfillment. King (1981) defines self as a composite of thoughts and feelings that constitute a person's awareness of individual existence, and a conception of who and what, he/she is. Persons' self is the sum total of all they can call their own. It includes among other things, a system of ideas, attitudes, values and commitments, and one's total subjective environment. The self constitutes a person's inner world as distinguished from the outer world consisting of all other people and things. The self is the individual as known to the individual. It is that to which we refer when we say 'I' (pp. 27-28).

Self is defined as "the total, essential, or particular being of a person; the individual. The essential qualities distinguishing one individual from another. Consciousness of one's own being or identity (Houghton Mifflin's College Dictionary, 1986, p. 1058).

In five qualitative studies, stroke survivors reported a loss of sense of self (Doolittle, 1991; Folden, 1994; Mumma, 1986; Secrest & Thomas, 1999). Stroke survivors were reported to focus not on what functions they had left but rather on what losses they had experienced and what the loss of functions meant to them (Doolittle, 1991; Folden, 1994; Haggstrom, Axelsson, and Norberg, 1994; Mumma, 1986; Secrest & Thomas, 1999). In the preliminary development of an instrument to measure disability perception, Laman and Lankhorst (1994) found a difference between objective disability and perception of disability (subjective). The researchers also indicated that coping mechanisms might influence the impact of a disability. Health care providers' perceptions of the patient's functional level were reported to be higher than the patients', which was significant (Mattie, Crisler, Campbell, & Woodruff, 1991; Mattie, Campbell, Crisler & Woodruff, 1992). These studies note that survivors' perceptions of their disabilities are different from that of healthcare providers.

According to King (1981) self is a composite of thoughts and feelings, which constitute a person's awareness of his/her individual existence, and a conception of who and what, they are. The stroke survivor's perception of level of disability is their assessment of their functionality, their awareness of their individual existence, and is therefore a logically substructed subconcept from self. The Visual Analog Scale (VAS) developed by Price, McGrath, Raffi, and Buckingham, (1983) is a subjective measurement of functioning, and is therefore a reliable measure of the stroke survivor's perception of level of disability. The VAS is at the interval level of measurement.

Health

King (1981) defines health as "dynamic life experiences of a human being, which implies continuous adjustment to stressors in the internal and external environment through optimal use of one's resources to achieve maximum potential for daily living" (p. 5). Health is a process of growth and development that is not always smooth and without conflict. Health relates to the way in which individuals deal with the stresses of growth and development while functioning within their sociocultural groups.

King (1990) notes that the characteristics of health are genetic, subjective, relative, dynamic, environmental, functional, cultural, and perceptual. The ability to maintain a level of health that enables one to perform the activities of daily living that lead to a relatively useful, satisfying, productive and happy life is one of life's challenges (King, 1981, 1990). Health is a function of persons interacting with their environment. Environment is a function of balance between internal and external interactions.

Health is also a functional state in the life cycle, and illness indicates some interference in this cycle. Functioning involves performance of ADLs in a manner that allows the individual to lead a relatively useful, satisfying, productive and happy life. Functioning or performance according to King (1981) depends on harmony and balance in the individual's environment. Health and illness are both dimensions in the life span of human beings whose meanings are influenced by culture, definitions of health, and environment.

King (1981) indicated that measurement of health is a worldwide issue. The traditional indicators of health, such as mortality and morbidity are not adequate, as they do not recognize the social, emotional, or economic consequences of illness. King suggested that measurement of health should include attributes that are essential for human beings to function in their roles, environmental factors, and the developmental process.

Health has a multiplicity of meanings. Health is defined as the overall condition of an organism at a given time with soundness, especially of body and mind. A condition of optimal well-being has been suggested (Houghton Mifflin, 1986, p. 569). The World Health Organization defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease" (WHO, 1980). In addition, health is defined as:

> A state of dynamic balance in which an individual's or a group's capacity to cope with all the circumstance of living is at an optimum level. A state characterized by anatomical, physiological, and psychological integrity, ability to perform personally valued family, work, and community roles; ability to deal with physical, biological, psychological and social stress; a feeling of well being; and freedom from the risk of disease and untimely death (Stedman's Medical Dictionary, 1997, p. 382).

There are multiple definitions of health, many related to the discipline defining it. For nursing health is viewed as a multidimensional phenomenon that is more than the absence of disease or illness (Smith, 1981). Smith (1983) proposed four models of health: the clinical model, the role performance model, the adaptive model, and the eudemonistic model. The clinical model has the narrowest view. Health is viewed as the absence of signs and symptoms of illness (p.47). The other models can be viewed as an expansion of the clinical model with the eudemonistic model embracing the concerns of the other three models and therefore is the most comprehensive. The adaptive model is most closely related to King's (1981) conceptualization of health. Health is viewed in relation to a person's interaction with the environment. King views health from a social role and general systems perspective. Health includes adaptive and functional potential and performance. Health is implied as a factor in life that allows one to function in one's usual role (King, 1994).

Health according to King (1981) includes the individuals ability to function in their usual roles, and performance of ADLs in a manner that allows the individual to lead a relatively useful, satisfying, productive and happy life, which are all congruent with the conceptualization of health-related quality of life. Therefore, health-related quality of life is logically substructed from health.

King does not define quality of life, however, she states that "the conceptual system is timeless and is not culture bound. It can be used at anytime in any culture because it provides structure to observe interacting elements in the environment that enhance or impinge on quality of life" (King, 1994, p. 30).

There is great diversity in the definitions of health-related quality of life (HRQOL). A conceptual formulation that has emerged in clinical setting defines it as "functionally by patients' perceptions of performance in four areas: physical and occupational, psychological, social interaction, and somatic sensation" (Schipper, Clinch, & Olweny, 1996, p. 11) that includes the essence of most definitions. Underlying this conceptualization is the subjective nature of HRQOL, interpersonal relationships within and outside the family, transaction between the person and the environment, which are influenced by socio-cultural factors. HRQOL is a narrower subset of the overall concept of QOL. It looks at QOL only in the health context. HRQOL includes the domains of physical, psychological, social, spiritual, and role functioning, as well as general well-being. Most definitions of QOL include the individual's degree of satisfaction and/or perception of satisfaction with life (Andrews, 1974; Hornquist, 1982; Oleson, 1990; Zahn, 1992).

Health-related quality of life is operationally defined as the individual's assessment of their energy, language, mood, personality, thinking, vision, mobility, upper extremity function, performance of self-care, family and social roles, and work/productivity as measured by the. Stroke-Specific Quality of Life scale ([SS-QOL], Williams, Weinberger, Harris, Clark, & Biller, 1999). The total and subscales scores are the empirical indicators. The level of measurement is interval.

Assumptions

King's (1981) conceptualizations and characterizations of relationships among personal system and the interpersonal system make it possible to make inferences about interaction, perception, self, and health. The following assumptions, derived from King's conceptual system for nursing serve as the basis for the proposed model of the theory of quality of life for stroke survivors (TQOLSS):

1. Perceptions of individuals determine their reality.
2. Perception influences the interactions of individuals.
3. Human interaction influences individual health.
4. Perception influences through interaction the health of individuals.
5. Social support is a human interaction and, therefore, influences individual health.
6. Health of individuals as a personal system is a multidimensional phenomenon.
7. Health has biological, psychological, social, and functional dimensions.
8. Health of individuals has structural and functional elements.

Propositions for this model are:

1. Perception affects all interactions, gives an individual a sense of self and others, and affects assessment of ones health-related quality of life.
2. Social support (a type of interaction) affects the stroke survivor's health-related quality of life.

King's (1981) framework and the literature review provide the basis for the hypothesized relationship between perceptual integrity, social support, perception of level of disability, and health-related quality of life (Figure 3). The hypotheses to be tested are:

1. *Perceptual integrity has a direct and positive effect on social support.
2. *Perceptual integrity has a direct and negative effect on perception of level of disability.
3. *Perceptual integrity has a direct and positive effect on the stroke survivors HRQOL.
4. Perceptual integrity has an indirect effect on the stroke survivor's HRQOL through perception of level of disability.
5. Perceptual integrity has an indirect effect on the stroke survivor's HRQOL through social support.
6. *Perception of level of disability has a direct and negative effect on the stroke survivor's HRQOL.
7. *Social support has a direct and positive effect on the stroke survivor's HRQOL
8. *Social support has a direct and negative effect on perception of level of disability

(* These hypotheses are mapped on Figure 3).

In addition, the research questions are (1) "How much of the variance in HRQOL is explained by the model?" and (2) "What is the relationship of age, time since stroke and number of strokes to health-related quality of life?"

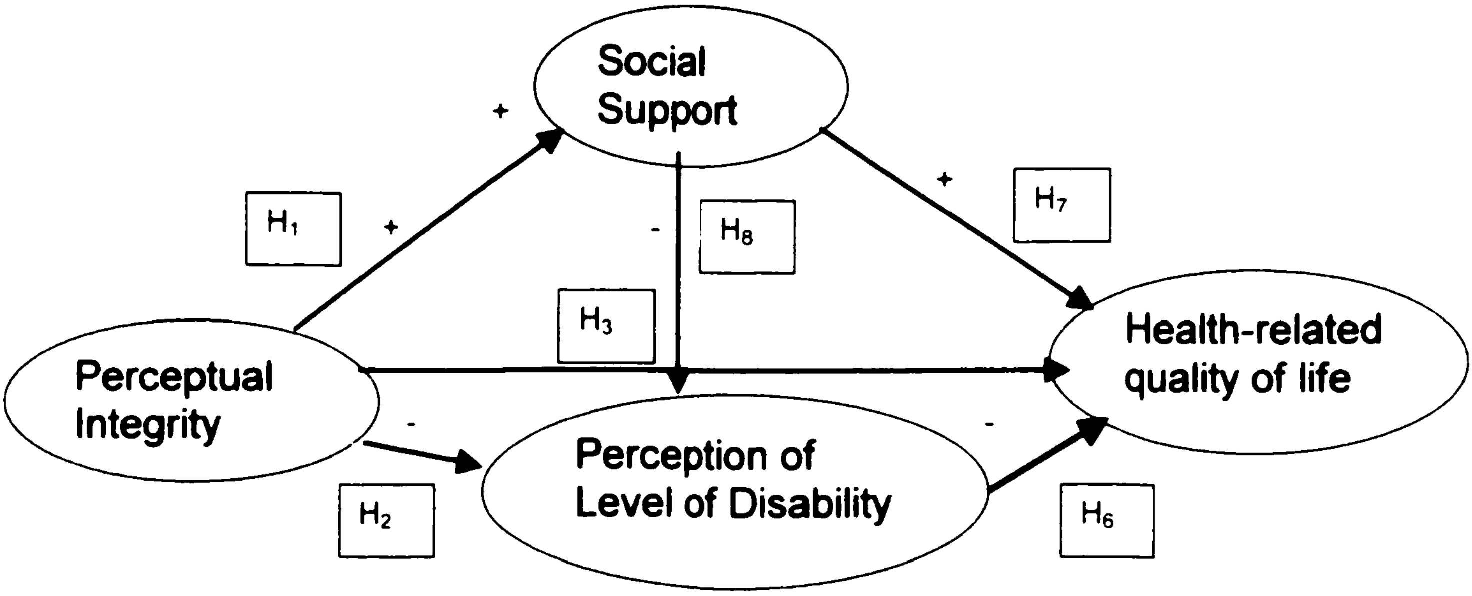


Figure 3.
Middle-range Theory of Health-related Quality of Life of Stroke Survivors
*Hypotheses 1, 2, 3, 6, 7, 8

CHAPTER 4

METHODS

Research Design

A descriptive correlational design was used to examine the quality of life of stroke survivors. Structural equation modeling (SEM) was used to test the middle-range theory of Quality of Life of stroke survivors (TQLOSS), which was derived from King's (1981) conceptual framework for nursing. The relationship among the variables: perceptual integrity, social support, perception of level of disability, and HRQOL was evaluated in assessing the fit of the proposed model (Figure 4). Age, number of strokes and time since stroke were included in the model as extraneous variables that could influence the quality of life of stroke survivors.

Prior to the main study, a pilot study was done to evaluate the reliability of the Stroke-Specific Quality of life ([SS-QOL], Williams et al., 1999) instrument, to determine the time that it would take for participants to complete the study questionnaires, and to identify any other problems related to administration procedures. Twenty subjects (N = 20) who met the inclusion criteria compromised the sample. Their data were used in this study. Findings from the pilot study indicated that the time needed for administration of the study instruments ranged from 30 to 50 minutes, mean = 35.5 (SD = 6.47); all participants requested that the investigator read the questions and record their answers except for the Visual Analog Scale. The SS-QOL 's reliability was similar to that reported by the creators . The result of the pilot study did not indicate the need for changes in either the procedure or the SS-QOL. A detailed description of the pilot study is in Appendix C.

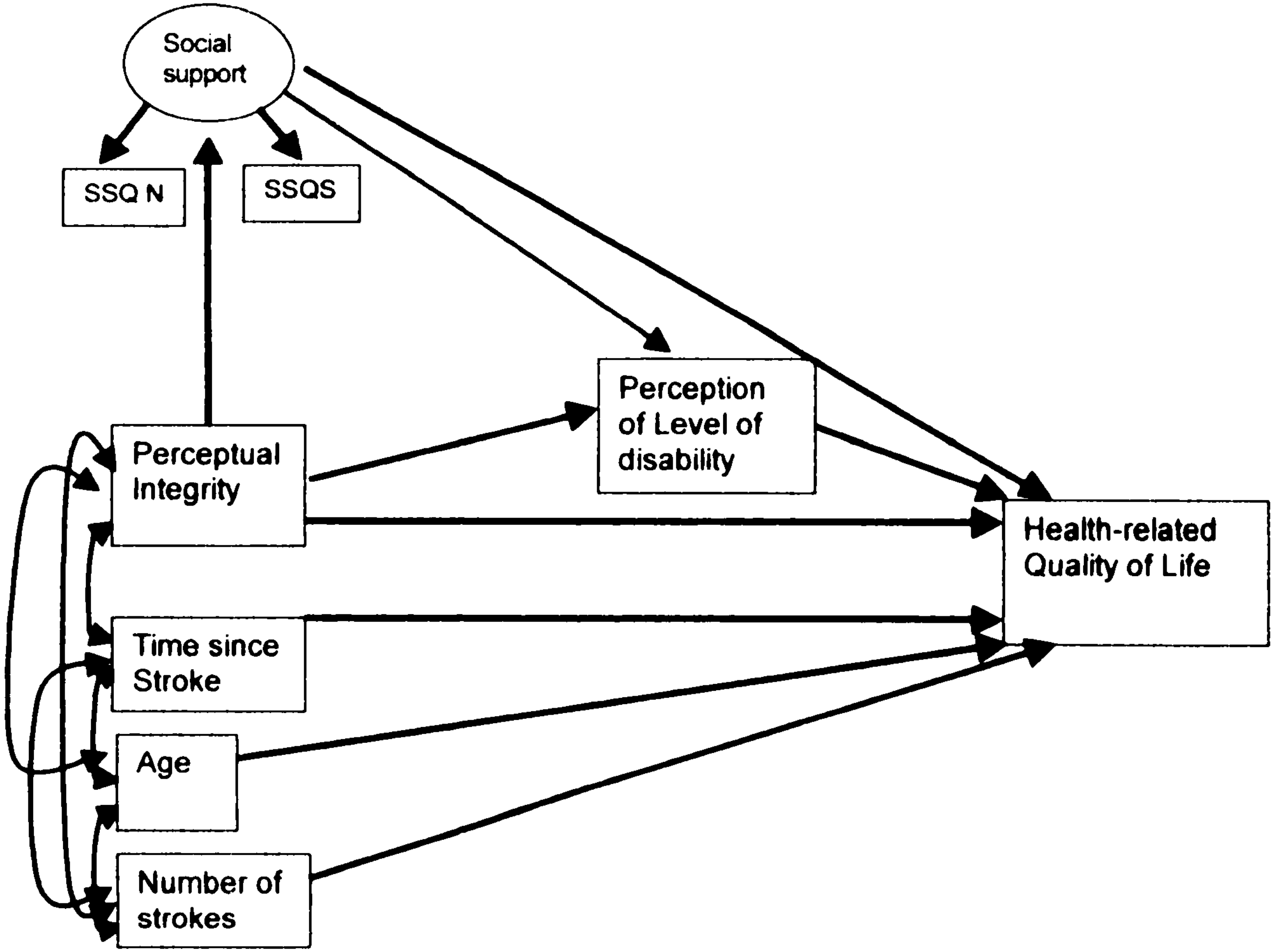


Figure 4.
Proposed Model of Theory of Quality of Life of Stroke Survivors

Sample and setting

The target population for this study was all stroke survivors as defined by International Diagnosis Codes (ICD) 9 codes 430-438. The accessible population was all stroke survivors who were receiving care at an acute care and/or rehabilitation hospital affiliated with an urban university in a large Southeastern Michigan city. The sample was a convenience sample of 102 stroke survivors who met the inclusion criteria. Convenience samples are accessible and require less time to acquire (Burns & Grove, 2001). Inclusion criteria: (1) over age 40, (2) able to understand and converse in English, (3) medically diagnosed with a stroke, (4) cognitively functioning at a level of 5 or better on Cognitive Subscales of the Functional Independence Measure (FIM), (5) at least four months post stroke, and (6) attending one of the clinics.

Sample Size

The proposed model (TQLOSS) has four exogenous and three endogenous variables. The recommendation for sample size is a ratio of 10:1 subjects per parameter. However, a ratio of no less than 5:1 is needed for statistical stability of the results (Kline, 1998). Kline considers 100 as a small sample size. In the TQLOSS, there are 17 parameters, therefore, a minimum sample size of 85 was needed (Youngblut, 1994; Kline). A target of 100 participants was established for this study.

One hundred and fourteen potential participants were identified. After the initial contact, eight refused to participate when contacted to set up a date for the interview, two refused to be interviewed on the date of their appointment, and two did not return calls to set up an appointment. The rate of refusal was 11 %.

The study sample consisted of 102 stroke survivors ranging in age from 43 to 93 years of age with a mean age of 63.21 (SD = 10.54) and a median of 61. Demographic characteristics of the sample including age, gender, ethnicity, marital status, religion, participation in religious activities, living conditions, employment status, educational level, and number of strokes are listed in Table 1. There were 64 females (63%), 83 African Americans (81%), and 75 were not married (74%). Seventy-five were protestant (74%) and the majority (70%) participated in religious activities at least once a year. Sixty-nine lived with another person. Forty-eight of the stroke survivors became disabled after the stroke, 34 had retired prior to the stroke, and 16 had returned to work. The educational levels ranged from 4 to 22 years, the median was 12 years, three completed masters degrees and two, professional doctorates. Seventy-four participants had had one stroke and two had had four strokes. Time since stroke ranged from four months (n=16) to 34 years (n=1), mean 32.59 (SD = 61.82). Surprisingly only 12 of the stroke survivors belonged to the Spice of Life Stroke Club, a support group at the Rehabilitation hospital.

Measures

Three independent (cognitive functioning, social support, perception of level of disability), three control (age, time since stroke and number of strokes) and one dependent variable (health-related quality of life) were assessed by self-report. Five instruments were used (See Appendix A). All were collected by this researcher. The theoretical concepts, an abbreviated statement of operational measures, and the internal consistency reliabilities of selected instruments used in this study are summarized in Table 2.

Demographic Questionnaire

A demographic questionnaire was used to collect information related to age, time since stroke, number of strokes, gender, ethnicity, marital status/cohabitation, religion, participation in religious activities, living conditions, employment status, education, membership in the Spice of Life Club (a stroke support group at the rehabilitation facility), and length of membership in the Spice of Life Club.

Table 1

Demographic Characteristics of the Study Participants (N = 102)

Characteristic	Number	Percentage
Gender		
Male	38	37.3
Female	64	62.7
Ethnicity		
African American	83	81.4
Caucasian	16	15.6
Hispanic	1	1.0
Native American	1	1.0
Multi-Racial	1	1.0
Marital Status		
Married	25	24.5
Single	17	16.7
Separated	6	5.9
Divorced	31	30.3
Widowed	21	20.6
Significant Other	2	2.0
Religion		
Catholic	13	12.7
Jewish	2	2.0
Muslim	1	1.0
Protestant	75	73.5
Other (SDA)	10	9.8
None	1	1.0

(table continues)

Table 1 (continued)

Demographic Characteristics of the Study Participants (N = 102)

Characteristic	Number	Percentage
Participation in Religious Activities		
Weekly	20	25.5
Monthly	25	24.5
1-2 a Year	21	20.6
Inactive	30	29.4
Living Condition		
Alone	32	31.4
Spouse/Significant other	27	26.5
Daughter/son	17	16.7
Relative	23	22.5
Friend	2	2.0
Nursing Home	1	1.0
Employment Status		
Working Full-time	11	10.8
Working Part-time	5	4.9
Retired	34	33.3
Disabled	48	47.1
Not employed	4	3.9
Educational Level		
Years 1-8	6	5.9
Years 9-12	58	56.8
Years 13-16	31	30.4
Years 17-22	7	6.9
Number of strokes		
One	74	72.5
Two	23	22.5
Three	3	2.9
Four	2	2.0

Table 2

Operational Measures of Study Concepts

Theoretical Concepts	Operational Measures	Range	Mean	SD	Skew	Kurtosis	Alpha
Age	Chronological age in years	43-93	63.21	10.54	.410	-.423	
Time since stroke	Time since stroke in months	4-411	32.59	61.828	4.422	22.633	
Number of stroke	Numerical count of strokes	1-4	1.34	.637	2.136	5.047	
Social Support	Scores on the Social Support Questionnaire Short Form Subscales						
	Number of perceived supports (SSQN)	0-9	3.54	1.93	.840	.449	.87
	and Satisfaction with support (SSQS)	2-6	5.68	.67	-3.44	13.545	.83
Cognition	Score on the cognitive subscale of the Functional Independence Measure (FIM)	53-100	77.09	19.10	-.744	-.285	
Perception of level of disability	A self-evaluation indicated by a horizontal mark on a 0 -100mm vertical bar on the Visual Analog Scale (VAS)	2-94	46.00	28.55	.010	-1.303	
Health related quality of life (HRQOL)	Total score on the Stroke-Specific Quality of Life Scale (SS-QOL)	96-241	175.4	32.860	-.215	-.714	.93

The Functional Independence Measure (FIM)

The cognitive subscale of the FIM was used as the empirical indicator for perceptual integrity. The FIM (UDS Data Management Service, SUNY Buffalo, 1993) was developed to provide a discipline-free reliable and valid measure of disability across numerous medical diagnoses (Granger & Hamilton, 1992). The scale was the product of a task force established by the American Congress of Rehabilitation Medicine and the American Academy of Physical Medicine and Rehabilitation in 1984. The task force reviewed more than 30 functional assessment instruments before deciding to develop their own (Granger, Hamilton, Keith, Zielezny, & Sherwin, 1986).

The FIM evaluates 18 activities of daily living, on a scale of 1 for complete dependence on others to 7 for complete independence. It can be used by a variety of health care professionals. Data are obtained by observation or telephone interview. The FIM has undergone extensive testing and revision. Psychometric properties reported for the FIM include face and construct validity, discriminant validity, interrater reliability and precision (Hall, Hamilton, Gordon, & Zasler, 1993). Face validity was established by having experts evaluate the items included in the measure. The task force identified 16 functional assessment items that pertained to a variety of rehabilitation impairments, such as stroke (Granger, et al., 1986). The list of functional assessment items was shared with other rehabilitation professionals at meetings in Florida and Boston, and an open forum was conducted to share initial findings.

Originally, the tracking of patient's progress relied on a summation of the total FIM score ranging from a minimum of 18 to a maximum of 126. The higher scores indicate better functioning. The raw scores are counts of levels of performance that the individual demonstrates. The raw scores were converted to interval level data through Rasch analysis. Rasch analysis is a statistical technique for constructing interval measures from ordinal data designed to be unidimensional. When the underlying variations in behavior are dominated by one dimension, each client can be characterized by a single latent ability measure, and each item by a single latent difficulty calibration both of which are positions along a shared linear measurement continuum. These latent measures and calibrations cannot be observed directly. Rasch analysis provides the means of calibrating a scale structure on which linear measures underlying the observations are defined. (Heinemann et al., 1993). Data from 27,669 patients in 13 impairment groups were included in the analysis. A consistent pattern was found across diagnoses. The FIM was found to have two components, one consisting of 13 items related to motor function, (with a range of raw scores between 13 and 91 and a corresponding range of Rasch scores being 0 to 100). The other component consists of 5 items related to cognitive function, (with a range of raw scores between 5 and 35 and a corresponding range of Rasch scores being 0 to 100).

Construct validity was established through the timing of caregiving tasks in the home by experienced clinicians, In one study, clinicians observed persons diagnosed with multiple sclerosis and their caregivers in the home, using multiple functional assessment (Granger, Cotter, Hamilton, Fiedler, & Hens, 1990). The FIM accounted for 99.8% of the variance in help in minutes a day when vision limitations were removed from the analysis; and from a ranking of the top 10 items related to help in minutes a day, the FIM was correlated with 8 of them (r = - 70 to -.84). It was, therefore, most useful for predicting the burden of care in minutes of assistance needed.

Discriminant validity has also been reported. Difficulties in performing certain tasks showed variations across impairment groups (Granger et al., 1993). Using factor analysis, data from all impairment groups were found to load on one factor for motor function, accounting for 95% of the variance. Data from all groups were also found to load on one factor for cognitive function, accounting for 92% of the variance (Heinemann et al., 1993). Difficulties on specific motor and cognitive items measured on the FIM were found to differentiate among orthopedic conditions, stroke with left hemiparesis, and spinal cord dysfunction when the Rasch scores were plotted . The relative difficulty of items across impairment groups parallels the actual nature of these groups' medical condition. For example, bladder and bowel dysfunction management were identified as relatively easier activities for stroke patients, and relatively more difficult for spinal cord injury patients. Feeding was a relatively less dysfunctional activity, whereas, stairs were a relatively difficult one for those with amputations. Expression of ideas was more difficult for persons with a stroke, social interaction were more difficult for persons with spinal cord dysfunction, and memory and problem solving was more difficult for persons with brain dysfunction (Heinemann et al., 1993).

Interrater reliability was determined to be the most useful form of reliability for this instrument since health care professionals would be using the FIM (Granger et al., 1986). When two or more pairs of clinicians assessed 263 patients from 21 rehabilitation facilities, the FIM was found to have good interrater agreement (Hamilton, Laughlin, Granger, & Kayton, 1991). The intraclass correlation coefficient exceeded the .90 criterion for the total FIM and for all six subscores. Another measure of interrater reliability is kappa, a measure of the intraclass correlation for each item, where a value of .40 to .75 indicates fair to good agreement beyond that due to chance (Hamilton et al., 1987). The kappa for individual FIM items was mean .71, with a range of .61 to .76 for the 18 items, exceeding the minimum criterion of .45 for 15 of 18 items set by the investigators.

In the present study, raw scores were recoded to Rasch scores (Heinemann et al.,1993). The Rasch scores for the cognitive subscale of the FIM ranged from 53 to 100 (raw scores 25 to 35), The mean score was 80.6 (SD = 13.44), median of 82, and a mode of 87. Overall, the cognitive functioning of the sample was quite high. The results were negatively skewed (-.017) based on the inclusion criteria of a score of 5 $\geq$ on the items of the cognitive subscale of the FIM to be eligible for participation. Impairments in the individual's internal nervous system, as may follow a stroke can alter the individual's cognition. King (1981) concurs that an altered nervous system may alter perception. The scores on the cognitive subscales of the FIM is an appraisal of the individual's level of comprehension, expression, social interaction, problem solving and memory.

The Social Support Questionnaire Short Form (SSQSR)

Social support was measured by the Social Support Questionnaire Short Form (SSQSR) by Sarason et al. (1987). The SSQSR was derived from the twenty-seven-item Social Support Questionnaire ([SSQ]. Sarason et al.,1983), which was designed to measure perceived number of social supports and satisfaction with the support that is available. The SSQ was derived by factor analysis from a large body of items intended to measure the functions served by social networks (Sarason et. al., 1983). The SSQ is composed of two subscales, the SSQ-N (numbers of support), and the SSQ-S (satisfaction with support).

The reported interitem correlations for the number (N) scores ranged from .35 to .71 with a mean interitem correlation of .14. The alpha coefficient for the N scores was .97. The reported interitem correlations for the satisfaction (S) scores ranged from .21 to .74 with a mean interitem correlation of .37. The alpha coefficient for the S scores was .94. Factor analysis (unrotated) showed that 82% of the common variance for the N score and 72% of the common variance in the S score was accounted for by the first factor. The factor loading exceeded .60 for the N score and .30 for the S score. The correlation between the N score and the S score was .34. The high internal consistency among items, modest correlations between the SSQ-N and the SSQ-S indicates internal reliability.

Test retest correlations for the N and S scores were reported as .90 and .83 respectively (4-week interval). This indicated the stability of the SSQ.

Construct validity was assessed by comparing scores with similar domains of established measures Multiple Adjective Affect Check List (MAACL), the Eysenck Personality Inventory (EPI) Extroversion and Neuroticism scales, and the Marlowe-Crown scale "Ladder of Life". Correlations between the SSQ-N and SSQ-S measures of social support and measures of emotional discomfort, such as the Anxiety, Depression, and Hostility scales from the MAACL were reported as being significantly negative (range -.30, -.31, and -.26 respectively) for women. Similar results were also reported for the Lack of Protection (LP) scale (-.32), whose items deal with recollections of separation anxiety in childhood. Extroversion measure for women was positively correlated with the SSQ-N (.35), whereas the Neuroticism measure was negatively correlated (-.15). The results for men were similar, however, the relations were not as strong. The correlation with the Marlowe- Crown scale of social desirability and the SSQ-N or SSQ-S was reported as not significant for either gender (Sarason et. al., 1983). Test-retest reliability was reported as r = .90 for the SSQN score and .83 for the SSQS score at a four-week interval.

The SSQSR (Sarason et. al., 1987) was developed from two studies, which were done to develop a three-item, and a six-item version of the SSQ to establish groups of items that correlated highly with the twenty-seven-item version and to determine the internal reliabilities and test-retest reliabilities. The short-and long-forms correlations were compared with relevant personality characteristics. The three-item form of the SSQ (SSQ3) appeared quite similar to the twenty-item version of the SSQ in its relationship to personality and social competence scales. Its test-retest reliability was reported acceptable, but its internal consistency (SSQ3-Number 0.75, and SSQ3-Satisfaction 0.79) was lower than the internal reliabilities of the SSQ (0.97), which was most likely due to the fewer items.

In a second study, the items were selected through statistical analysis rather than a priori. This selection was more likely to be representative of the SSQ as a whole. Three independent samples from a database were used. Sample 1 consisted of 182 psychology students used in the SSQ study. Sample 2 was comprised of 81 males and 136 females enrolled in a psychology class. Sample 3 consisted of 59 male and 87 female psychology students. Factor analysis using principal factors with Varimax rotation were done for sample 1 and 2, and the data analyzed separately. First, the SSQ Number and Satisfaction items were combined for each sample in the analysis and then separate analyses were done. The analyses for Number and Satisfaction items separately were used. The highest six loadings in each analysis were identified and then averaged across number and satisfaction items to yield Number-Satisfaction pairs rank-ordered by the magnitude of the average loadings. This produced six pairs for sample one and seven pairs for sample two. The sample one loadings ranged from 0.78 to 0.82, while those for sample two ranged from 0.76 to 0.80. Six items were selected for further study, three items were common to the two samples and the other three items were selected because they ranked as high or higher than the common items in one of the two samples. The internal reliabilities of the SSQ6 ranged from 0.90 to 0.93 for both Number and Satisfaction. The correlations of the SSQ6 and the SSQ were compared with a variety of social support indices and no significant differences were found.

The SSQ6 (SSQSR) has been in used studies with clients with cardiac arrhythmia (Thomas, Friedmann, Wimbush, & Schron, 1997), patient and spouse adjustment to recurrent breast cancer (Northouse, Laten, & Reddy, 1995), comparison of outcomes and practices in African Americans and Caucasians with diabetes (Bailey & Lherisson-Cedeno, 1997), clients with osteoarthritis (Blixen & Kippes, 2000), and stroke patients (Chang, MacKenzie, Yip, & Dhillon, 1999). Reported reliability of the SSQSR in these studies ranged from .86 to .93 (Bailey & Lherisson-Cedeno; Northouse).

In the present study, internal consistency was examined using Cronbach's Alpha for the SSQSR and the subscales SSQN and SSQS. The alpha coefficients were .84, .87 and .83, respectively, which are satisfactory. The SSQSR represents the individual's assessment of their social interaction with family, friends, neighbors, and others along with their satisfaction. The quality of the interactions influences health, therefore, their assessment of their support can be expected to influence their quality of life (King, 1981).

Visual Analog Scale

A Visual Analog Scale (VAS) was used as an empirical indicator of perception of level of disability. The VAS is a straight line. The end anchors of which are labeled as the extreme boundaries of the response to be measures, which were "not disabled" and "very disabled" in this study. Price, McGrath, Raffii, and Buckingham (1983) reported the results of their study to examine the validity and reliability of the VAS as a tool for assessing the intensity and affective domains of pain in 30 patients with chronic pain and 20 healthy volunteers. Each subject participated in two experimental session in which they used the VAS to rate sensation intensity and affective magnitude of the pain evoked by heat pulses at 43, 45, 48, 49 and 51° C. All subjects scaled similarly the sensation intensity and the affective magnitude of noxious heat pulses; between subjects variability was small (r not reported). Between session reliability was high ($r = .97$). There were no significant differences between the healthy volunteers and the chronic pain patients in their sensory or affective VAS responses. The authors also reported that patients scaling of experimental and chronic pain were matched to three levels, which demonstrated internal consistency of the VAS, thereby demonstrating the valid use of VAS for the measurement of an comparison between chronic pain and experimental heat pain.

The VAS has been used as a measure for childbirth experiences (Harrison, 1991), food preferences in anorexia and bulimia nervosa (Stoner, Fedoroff, Anderson, &

Rolls, 1996), fatigue in HIV patients prior to AIDS (O'Dell, Meighen, & Riggs, 1996), nurses attitudes to attempted suicide patients (Samuelsson, Sunbring, Winell, & Asberg, 1997), congruence in patients' health status by patients and their physicians (Suarez-Almazor, Conner-Spady, Kendall, Russell, & Skeith, 2001), grief in spouse and children caregivers of dementia patients (Lindgren, Connelly, & Gaspar, 1999) self-reported fatigue in rheumatoid arthritis (Tack, 1990) and quality of life in stroke survivors (Ahlsiö et al.,1984, Kwa, Limburg, & de Haan, 1996). The foregoing studies indicate the VAS as a reliable method for assessing perception of level of disability.

The participants in this study found the VAS easy to use. The VAS is a vertical line measuring 100 mm, the bottom anchor (0 mm) was labeled "not disabled" and the top anchor (100 mm) was labeled "very disabled". The individual's were asked to draw a horizontal line across the vertical line to indicate how disabled they think they are, the marks were measured with a ruler. Scores ranged from 2mm to 94mm, with a mean of 46 (SD = 28.55) and a median of 51.5. The range in scores indicates that the VAS is a valid measure of the study participants perception of their level of disability. According, to King (1981) self encompasses the individual's system of ideas, attitudes, values and commitments, and is their total subjective environment. The individual's assessment of their level of disability as marked on the VAS is their subjective perception of their functional ability.

Stroke-Specific Quality of Life Scale

The Stroke-Specific Quality of Life Scale (SS-QOL) was used as the empirical indicator for health-related quality of life (Williams et al., 1999). This instrument was developed specifically to measure health-related quality of life (HRQOL) in stroke patients. There are only preliminary results regarding reliability and validity of the SS-QOL at this time. Generic measures of quality of life are designed to compare HRQOL across populations or different diseases whereas; disease-specific measures are designed to assess HRQOL with questions and scales that are specific to a disease. The SS-QOL has 49 items that ask questions about functions typically affected by stroke.

The SS-QOL consists of twelve domains: energy, family roles, language, mobility, mood, personality, self-care, social roles, thinking, upper extremity function, vision, and work/productivity, which were identified by 32 poststroke patients. The original scale consisted of 78 items within these twelve domains. The authors developed three sets of responses on a 5-point Likert scale: (1) amount of help required to do specific tasks, ranging from no help to total help, (2) amount of trouble experienced when attempting tasks, ranging from unable to do it to no trouble at all, and (3) degree of agreement with statements regarding their functioning, ranging from strongly agree to strongly disagree. Subjects were told what set of responses to use for each question and the past week was the point of reference. The study population consisted of 72 patients with a mean age of 61 years (SD =13) ; 63% male, 25% black, and 18% had no health insurance. Most had mild strokes. Fifty one percent had lacunar strokes, 61% had strokes $\leq$ 1 cm on CT or MRI, and 58 % of the strokes were in the deep gray or subcortical white matter. In addition to the individual items of the SS-QOL, subjects were asked to rate each domain and their overall HRQOL compared with before the stroke as a lot worse, somewhat worse, a little worse, or the same. Overall HRQOL was rated as the same as prestroke in 48% and 59% at 1 and 3 months, respectively.

The number of items was reduced to 49 after evaluation with exploratory factor analysis, Cronbach's α, and change in mean item score between 1 and 3 months. The alpha coefficient for the domains was reported to range from .73 to .89.

Construct validity was assessed by comparing the scores with similar domains of established measures (Medical Outcomes Short Form Health Survey [SF-36], Beck Depression Inventory [BDI], National Institutes of Health Stroke Scale [NIHSS] and

Barthel Index [BI]). One month scores on energy, family roles, mobility, mood, personality, self-care, and work domains were reported to be significantly linearly associated with the corresponding scores of the BI, BDI, and subscales of the SF-36 (r^2 range .3 to .5). Scores in the language and thinking domains were reported as not being associated with selected items from the NIHSS ($r^2 = .1$). This lack of association was explained to be most likely due to the exclusion of patients with language and cognitive deficits (there were no patients with a score >1 on these items). The lack of linear association in the upper extremity domain ($r^2 = .18$) was explained as being most likely due to the ceiling effect of the NIHSS, although 62% of patients reported upper extremity dysfunction one month after stroke, only 11% had an NIHSS arm score >1. A significant ceiling effect was also reported for the BI (81% with a score $\geq$ than 95), and a moderate flooring effect for the SF-36 role limitation subscale (49% with score = 0). The SS-QOL social roles domain was reported as not being linearly associated with the SF-36 social functioning subscale score ($r^2 = .01$). The mean social roles domain scores were significantly different in patients reporting their social roles as a lot worse, a little worse, and the same as before stroke (mean domain scores, 1.98, 2.87, and 3.07 respectively; $p = 0.006$), but mean SF-36 social functioning scores were not different in these groups (48, 50, and 47, respectively; $p = .84$).

The authors reported that domain responsiveness was assessed between one and three months after stroke in subjects affected in that domain. Most of the domains demonstrated moderate responsiveness, with standardized effect size (SES) scores ranging from 0.20 to 0.83. The mood and personality domains were reported to be less responsive across all instruments: SES scores for the BDI and SF-36 mental health subscale were <0.2.

The authors stated that there were questions that needed to be answered, the issue of proxy respondents, interviewer versus self-administration, weighted versus unweighted domains, and performance in patients with more severe stroke. Revalidation of the SS-QOL, in a larger sample that includes patients with more severe stroke is reportedly underway.

A follow-up study (Williams, Weinberger, Harris & Biller, 1999) was done using the SS-QOL to identify the predictors of poststroke HRQOL in patients with mild to moderate ischemic stroke and too compare the ability of the SS-QOL with that of a generic scale for predicting overall HRQOL poststroke. The samples consisted of 71 patients who were evaluated at one month poststroke with the SS-QOL and the SF-36 (a generic HRQOL measure). The participants mean age was 61 years, 63% were male, and 25% African American. Most had a mild stroke with a mean Canadian Neurologic Scale score on admission of 9.2 ± 1.9 (SD, range, 2.0 to 11.5, best possible score, 11.5). Stroke related impairments scores were ≥ 1 in 43% of the patients as measured by National Institute of Health Stroke Scale (NIHSS). Disability measured by the Barthel Index was ≥ 95 in 81% of the patients. The mean SF-36 (a generic HRQOL measure) score was 56 ± 16, and the mean SS-QOL score was 3.8 ±.07. HRQOL was rated the same as prestroke by 48% of the patients. Thirty-nine percent met the criteria for at least mild depression (Beck Depression Inventory [BDI]). The variables that were significantly associated with the patients' overall HRQOL rating were SS-QOL, NIHSS, and the BDI scores. Age, gender, ethnicity, and SF-36 scores were not associated with overall HRQOL rating. Multivariable modeling with NIHSS, Barthel Index, BDI, and SS-QOL scores as independent variables showed that the odds of HRQOL being the same as prestroke were associated with higher (better) SS-QOL scores (OR, 2.97; 95% CI 1.3, 7.1) and lower (better) NIHSS scores (OR, .069; 95% CI, 0.47. 0.99). All domain scores except for upper extremity were either the same or higher in the group with better HRQOL, only the family roles domain was significantly different, with higher (better) scores in those with better overall HRQOL, (mean score 4.0 versus 3.4 $p = 0.04$).

Saladin (2000) reviewed generic instruments that have been use to examine QOL poststroke and stroke specific QOL instruments to evaluate their advantages and disadvantages. The generic instruments are the Medical Outcomes Short Form Health Survey (SF-36), the Euroqol (both have reliability and validity specifically established for stroke survivors), the Sickness Impact Profile (SIP), the Quality of Life Index (QLI), the Reintegration to Normal Living Index (RNLI), and the Nottingham Health Profile (NHP). The SF-36 and the Euroqol have been reported to have significant floor and/or ceiling effects. These instruments, therefore, have a reduced ability to accurately document QOL for those individual who report either very low or very high QOL, and may not accurately reflect treatment effects for the two groups. The stroke specific instruments are the Stroke Adapted Sickness Impact Profile (SA-SIP30), the Stroke Impact Scale (SIS), and the SS-QOL. The SIS and the SS-QOL were reported to have the advantage over the generic instruments and the SA-SIP30 in that they were "designed specifically to address the items most relevant to stroke survivors and that they may prove to be more valid measures of poststroke QOL with a superior ability to identify meaningful change" (p. 4). However, the SIS and the SS-QOL have just recently been developed, and therefore, there is minimal data published regarding their use, and reliability and validity testing is incomplete. The complexity of the SS-QOL was viewed as a limitation in that there are three different sets of responses to answer the items. The author also indicated that the wording of some items does not match the response set, for example, the item related to language reads "Did you have to repeat yourself so others could understand you?" and the matching response asks the individual to rate how much trouble they had with the task. The SS-QOL was judged as being the most sensitive to monitor individual change within patients.

Given the foregoing, this investigator feels that the reported reliability and construct validity of the SS-QOL is satisfactory for use in the population of study. The trouble they had with the task. The SS-QOL was judged as being the most sensitive to monitor individual change within patients.

Given the foregoing, this investigator feels that the reported reliability and construct validity of the SS-QOL is satisfactory for use in the population of study. The review by Saladin (2000) also indicates that it is most likely the best of the instruments available to measure HRQOL of stroke survivors. The investigator in this study found that only a few participants asked for clarification in questions such as the one cited by Saladin. Further, this author will be participating in further validation of the SS-QOL by submission of data, from the proposed study, to the developers.

Construct validity of the SS-QOL was demonstrated by the significant correlation $r = .489$, $p < .001$ with a single item measure of change in quality of life. This single item indicator use a four point scale to provide a self-evaluation of change in QOL: 1 = "a lot worse than before the stroke", 2 = somewhat worse than before the stroke", 3 = a little worse than before the stroke", and 4 = the same as before the stroke".

Internal consistency of the domains and the total score were examined with Cronbach's Alpha. In this study, the total score was used in the analysis. The alpha coefficient for the total score of the SS-QOL was .93. The alpha coefficients for the subscales ranged from .59 (personality) to .86 (mobility) reflecting adequate to good reliability. The individual's scores on the subscales indicate their assessment of their abilities to carry out self-care measures, perform their normal roles in the family and society, and their overall satisfaction with their productivity and life, all of which are congruent with King's (1981) conceptualization of health.

Intercorrelations of demographics and major study variables are listed in Table 3 and Intercorrelations of demographics and subscales of the SS-QOL are in Table 4.

There was no significant difference in quality of life between males and females $t(100) = .135$, $p = .89$. When compared by ethnic groups (white versus non white) there

Table 3

Intercorrelations of Demographics and Major Study Variables

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Age	1.00												
2. Number of strokes	.17	1.00											
3. Time since stroke	.15	.04	1.00										
4. Gender	-.15	.13	.04	1.00									
5. Marital status	.13	.24**	-.08	.16	1.00								
6. Ethnicity	-.003	-.04	10	.02	-.05	1.00							
7. Participation in Religious activities	.28**	-.08	-.02	-.11	-.06	.06	1.00						
8 Educational level	-.21**	-.15	-.09	.13	-.15	.13	-.06	1.00					
9. Cognition	-.17	-.07	.03	.20	.04	.19	.02	.41**	1.00				
10. Perception of level of disability	.03	.23**	.04	.01	.22*	-.29**	-.11	-.20**	.29**	1.00			
11. Social support numbers (SSQN)	.05	-.20*	.10	.14	-.12	.09	.08	.16	.17	-.25*	1.00		
12. Satisfaction with support (SSQS)	.15	-.14	.06	.09	.14	.05	.10	.00	.07	-.21*	.32**	1.00	
13. HRQOL (SS-QOL total)	.07	-.14	.09	-.01	.10	.18	.09	.31**	.28**	-.46**	.20*	.22*	1.00

*p < .05 **p<.01

Table 4

Intercorrelations of Demographics and SS-QOL Subscales

Variables	SC	V	W	UE	P	MD	FR	SR	E	T	L	M
Age	-.11	.07	-.06	-.10	.15	.22*	.15	.02	.07	.23*	.21*	.22*
Number of strokes	.04	.01	-.07	.01	-.23*	-.13	-.11	-.04	-.19	.20*	-.01	-.12
Time since stroke	.11	.08	.16	-.04	.09	.05	-.01	.10	.06	.22*	-.12	.03
Gender	.04	.01	-.01	-.06	.04	.01	-.08	.07	-.02	.07	-.04	-.00
Marital status	.07	-.12	-.17	.08	-.01	-.15	.07	-.09	-.08	.07	.08	-.09
Ethnicity	.16	.16	.15	.12	.06	.06	.06	.23*	.11	.11	-.03	.16
Participation in religious activities	-.07	.06	-.01	-.01	.08	.17	.16	-.06	.01	.17	.29**	-.04
Educational level	.26**	-.04	.28**	.19	.25*	.22*	.06	.26**	.22*	.22*	.15	.20

SC = self-care V = vision W = work/productivity UE = upper extremity function P = personality MD = mood
FR = family roles SR = social roles E = energy T = thinking L = language M = mobility
* p < .05 **p < .01

were no significant differences in QOL total score t(100) = -1.825, p = .07 and no significant differences in eleven of the twelve subscales (all p > .05). However, a significant between group difference was observed in the mean score on the social roles subscale which persisted F(2,99) = 4.370, p = .04 even after controlling for education as a covariate. Marital status was recoded into three groups married/significant other, single, and separated/divorced/widowed. There was no significant difference in quality of life based on marital status F(2,99) = .525, p = .593. By ANOVA the mean quality of life differed by employment status F(4.99) = 7.7, p < .001. Post hoc analysis using a Bonferroni correction (α = .05) to control for Type I error was conducted to isolate specific between group differences. Results of this analysis showed that mean quality of life for person employed fulltime (mean = 214.27) was significantly greater than the mean QOL of the retired (171.67, p = .001), and the disabled persons (165.16, p = < .001), but no other significant between groups differences were found.

Data Collection Procedure

The project was approved by the Human Investigation Committee (HIC) at the University and the two clinics. Potential participants were identified by the physicians and other staff members at both clinics and introduced to this investigator. The purpose and procedure of the study was further explained to the stroke survivor by the investigator. If the individual indicated that they would like to participate, an appointment was made for the interview and they were given a copy of the letter of Request for Participation (Appendix B) with the date and time of the interview written on it. The Request for Participation letter was also given to persons by the clinic staff when the investigator was not in clinic.

Data were collected in a one-time interview using the measures identified earlier (Appendix A). At the designated time and place for the interview the study was again explained to the participant and written consent obtained (Appendix B). Seven participants were interviewed at the time of the original contact at the clinic, one interview was done in a parked car as requested by the participant (the investigator picked up the participant at her place of work and found a quiet place to park and conduct the interview), and all others were interviewed at home at a time that was mutually convenient. The participants were given the choice of completing the measures themselves or having the investigator read the questions and record their answers. All chose to have the investigator read the questions and record their answers for all the measures except the VAS. The cognitive subscales of the FIM was always done first and the other three measures were randomly administered to lessen bias that might occur as a result of responding from one measure to the next. The interviews took between 30 to 45 minutes.

Human Subjects Consideration

The rights of the participants as research subjects were protected in the following manner. The proposal was submitted to the Human Investigation Committee (HIC) at the University for approval. HIC approval was obtained prior to recruitment of subjects. Each participant was given an identification number, which was used on the consent and all the questionnaires. The signed consent forms with identifying information was separated from the questionnaires after the interview and kept locked. Participants were informed that taking part in the study was voluntary and included their right to refuse to participate or withdraw at any time during the interview. They were assured of confidentiality and anonymity and that data from the study would be reported in aggregate form only. All information was kept in a locked file cabinet where it will be kept until it is shredded five years after completion of the study. There was no physical harm anticipated from participating in this study; however, some participants exhibited sadness when answering questions about the effects of the stroke, the investigator allowed them to pause and assured them that it was okay to cry. After a suitable period, they were asked if they wanted to continue. No one asked for the interview to be stopped. All subjects who completed the interview were given a $15.00 gift certificate to Kmart stores as a thank you for their participation. Appendix A contain the HIC approval of the original proposal and the amended changes, the consent form, the original letter for request for participation, and the amended one.

Data Analysis

Data Management

This investigator prepared the data-coding workbook, data entry was done by a research assistant and the investigator; data screening, data cleaning and editing, and data analysis were done by the investigator. Total scores were used for social support, cognitive functioning, and health-related quality of life. The VAS, age, number of strokes, time since stroke, and level of education, were coded as the raw data. Categorical variables were dummy coded (e.g. gender – female = 1, male = 0; ethnicity – African American = 1, Asian = 2, Caucasian = 3, Hispanic = 4, Native American = 5, Other (specify) = 6). The SPSS software program was used for data processing and preliminary analysis. Amos 4.0 software was used for SEM analysis.

Preliminary Analysis

A preliminary analysis was done to screen for accuracy of data entry and coding, missing data, and to test the assumptions of multivariate analysis. There were some missing data and data that were outside of coded values, these were easily adjusted after referring to the interviews. Once the accuracy of data entry and coding was completed, there was no missing data, testing assumptions of multivariate analysis were performed.

Testing for Multivariate Assumptions

Structural equation modeling is an extension of multivariate procedures such as multiple regression, path analysis and factor analysis. Therefore, assumptions of normality, absence of outliers, linearity, homoscedasticity, and absence of multicollinearity must be met.

Normality

Multivariate normality a common assumption of the data in SEM can be assessed by statistical or graphical methods (Tabachnick & Fiddel, 1996). Skewness and kurtosis statistics of each measured variable was used to assess normality. Variables with an absolute value of skew ≥ 2 or and actual kurtosis ≥ 7 are considered to depart from normality (Li, et al., 1998). Most of the variables were normally distributed except for number of strokes (skew = 2.136), time since stroke (skew = 4.22, kurtosis = 22.633) and satisfaction with social support (skew = -3.437, kurtosis = 13.546). Histograms also revealed skewness and kurtosis in the above variables, these three were independent variables. The number of strokes and times since strokes were not expected to be normally distributed in the population. Satisfaction with social support, (one of the indicators of social support) was expected to be normally distributed in the population. However, comments made by the participants during the interview indicated that they only listed persons in their network that they could depend on and were very satisfied with regardless of the number in the network. This resulted in a very negatively skewed and kurtotic distribution; severe skew and kurtosis can lead to biased results (Tabachnick & Fiddel, 1996). Next, a histogram of the Studentized Deleted Residual and a normal probability plot of the residuals were used to graphically test for multivariate normality. Findings indicated that the residuals of all variables were approximately normal; therefore, the assumption of normality of residuals was plausibly met and a decision to retain the skewed variables was made.

Outlier

Outliers are cases with such extreme values on one variable or a combination of variables that they can distort the statistics (Tabachnick & Fiddel, 1996). Outliers were assessed by two methods. Univariate outliers were identified by examining the data graphically with box plots and histograms. Multivariate outliers were identified using Mahalanobis distance (outliers on the set of predictor variables), Studentized Deleted Residuals (outliers on criterion variable), and the Cook's distance was used to assess the influence of outliers. Cases with Cook's ≥ 1 are considered influential cases (Tabachnick & Fiddel, 1996). Outliers were found on the predictors (Cases # 27, 29, 32, and 96), no outliers were found on the criterion, and no influential cases were found, therefore the decision was made to retain all the cases in the model.

Linearity

The linearity assumption is that there is a straight-line relationship between two variables (a predictor and criterion) such that the relationship between the two variables remains consistent (Tabachnick & Fiddel, 1996). Linearity was evaluated using bivariate and regression plots. Scatterplots revealed linear relationships between the pairs of variables. In addition, a linear relationship was shown between the predicted values of predictor variables and the residuals. These findings indicate that the assumption of linearity was met.

Homoscedasticity

Homoscedasticity refers to the assumption that the variability in scores for one continuous variable is roughly the same at all values of another continuous variable. This is related to the assumption of normality because when the assumption of multivariate normality is met the relationships between variables are homoscedastic (Tabachnick & Fiddel, 1996). Examination of a scatterplot of Studentized residuals against standardized predicted values showed no heteroscadisticity.

Multicollinearity

Multicollinearity occurs when independent variables are too highly correlated ([$\geq$ .90], Tabachnick & Fiddel, 1996). Bivariate multicollinearity was assessed by examination of the correlation matrix. The highest bivariate correlation between the independent variables in this study was between perception of level of disability and age, r = .29, p = <01 (See Table 5). Other criteria for multicollinearity are conditioning index > 30 and at least 2 variance proportions > .50 for a given root number (Tabachnick & Fiddel, 1996). The highest conditioning index was 22 and there were no variance proportions > .50 indicating no multicollinearity.

Analysis of the Proposed Theoretical Model

A structural equation modeling technique (SEM) was used to test the proposed theoretical model of the middle range theory of quality of life of stroke survivors (TQLOSS). SEM takes a confirmatory (i.e., hypothesis testing) approach to analyzing structural linkages within a proposed theoretical model by mathematically combining a variant of confirmatory factor analysis with path analysis. SEM provides a powerful tool for evaluating relationships among variables (Byrne, 2001). Although some authors state that SEM allows statement of causality to be made using correlational rather than experimental design, this is inaccurate. SEM can only provide the necessary but not sufficient evidence of causality and can provide an alternative methodology to experimentation for examining plausibility of hypothesized models (Hoyle, 1995; Maruyama, 1998). None the less, it is a valuable technique for nurse researchers who work with complex theoretical constructs that involve indirect and reciprocal relationships, using latent variables that are measured by multiple indicators (Boyd, Frey, & Aaronson, 1988).

The advantages of SEM are it allows for: 1) a more precise estimation of the indirect effects of the exogenous variables on all endogenous variable, 2) measurement

Table 5
Correlation Matrix of Observed Variables

Variables	1	2	3	4	5	6	7	8
1. Age	1.00							
2. Number of strokes	.17	1.00						
3. Time since stroke	15	.04	1.00					
4. Cognitive Function	-.17	-.07	-.03	1 00				
5. Perception of level of disability	.03	.28**	.04	-.29**	1.00			
6. SSQN (Number in network)	-.05	-.20*	-.10	.17	-.25*	1.00		
7. SSQS (Satisfaction with support)	.15	-.14	.06	.07	- 21*	32**	1.00	
8. Health related quality of life	.07	-.14	.09	28**	-.46**	.20*	.22*	1.00

* P<.05, ** P<.01 (2-tailed), N =102

separately account for unreliability of measures and for unexplained variances in factors, thus identifying if the problem is with measures or with misspecification of the theoretical model (Byrne, 2001; Kline, 1998).

Three strategies are used in model construction and development in SEM: they are strictly confirmatory, alternative models, and model generating. The strictly confirmatory strategy involves construction of one model and evaluations of its fit to appropriate data. If the model's parameter estimates are interpretable and fit the data well, then the model is considered reasonable. If the model does not fit, that is the end. In alternative models, a number of a priori models are specified and each model is fitted to the data. These models may be based on competing theoretical positions or conflicting empirical evidence. The models can be compared based on cross-validity. In model generation, the researcher specifies one model and fits it to the data, then evaluates the fit for the purpose of modifying the model to improve its parsimony and/or fit. The model may be simplified by deleting or adding selected parameters or introducing additional parameters. Model generating, which, was used in this study, is the most commonly used approach (Kline, 1998). This investigator specified the initial model and then tested it against the obtained data. It was anticipated that some modification would be needed, and that the modifications would be based on the statistical analysis. However, final changes would be made only if they were logically and theoretically sound.

A SEM model is comprised of two elements, the measurement and the structural model. The measurement model specifies how the latent variables are measured in terms of the observed variables, and describes their reliability and validity (measurement properties). Confirmatory factor analysis (CFA) methods are used to test the measurement model (Mueller, 1996). The structural model specifies the direct and indirect relationships among the latent variables and is used to describe the amount of explained and unexplained variance (Schumacher & Lomax, 1996).

Testing of the measurement model involves a series of regression equations to determine how well the observed indicators measure the latent variables (Maruyama, 1998). In this study the measurement model was not tested separately but with the structural model because there was one latent variable with only two factors.

The initial structural model was proposed to test the hypothesized relationships among the variables perceptual integrity (cognition), social support, perception of level of disability, and health-related quality of life. In addition, the relationship of age, number of strokes and time since stroke to health related quality of life was also assessed in the analysis of the full latent model. The structural model is made up of exogenous and endogenous variables. Exogenous variables, also called source variables, have their cause outside the model and are independent of other variables in the model, they have arrows that lead from them. In the TQLOSS, the four exogenous variables are perceptual integrity, age, number of strokes, and time since stroke. The endogenous variables are social support, perception of level of disability and health-related quality of life.

There are two types of SEMs, recursive and nonrecursive. Recursive models are systems that contain no reciprocal causation or feedback loops, the disturbance (random error) in the relationships between the exogenous and endogenous variables are uncorrelated. Nonrecursive models contain reciprocal causation, feedback loops, or have correlated disturbances (Kline, 1998). The TQLOSS is a recursive model

Testing of the structural model is done by using path coefficients to provide estimates of the strength of all hypothesized relationships in the theoretical model. Testing of the structural model provides information about the significance of the contribution of the predictor variables to the model and the amount of the variance in the criterion variable that is explained (Jöreskog, 1993).The output from a SEM analysis provides the information for model evaluation and assessment of fit.

Overall model fit

The overall model fit was assessed by examination of fit indices. A model is said to have a "good" fit if there is a fit between the sample covariance matrix and the estimated population covariance matrix. There are many fit indices but there is no agreement about a single optimal test or set of optimal tests (Maruyama, 1998). However, the three types of fit measures that have been classified in the SEM literature are absolute fit, relative fit (comparative or incremental fit), and adjusted or parsimonious fit (Maruyama; Kline, 1998). Many fit indices are based on chi-square estimates.

The chi-square statistics tests the null hypothesis that "there is no significant difference between the proposed and observed covariance matrix". In SEM, the researcher does not want to reject the null hypothesis but accept it, which, is contrary to most statistical analysis. A significant χ^2 would seem to indicate that the model does NOT fit, and that there are differences between the specified model and the study data. A nonsignificant χ^2 value indicates that the two matrices are not statistically different, which is what the researcher wants (Schumacher & Lomax, 1996). A major limitation associated with the chi-square statistic is its sensitivity to sample size. Large samples may yield significant χ^2 statistic even though differences between observed and model-implied covariances are slight (Kline). Therefore, it is recommended that a number of fit indices that address different estimates of model fit be addressed. The recommended set includes indicators of absolute fit, relative fit, and parsimony (Hu & Bentler, 1995; Kline, 1998; Maruyama, 1998).

<u>Absolute fit indices</u>. Absolute indices determine if the unexplained variance remaining after model fitting is significant. Absolute indices are based on the chi-square

statistic and include the CMIN (minimum discrepancy) and CMIN/df (χ^2/df). CMIN/df, which is a ratio of chi-square to degrees of freedom, attempts to correct for the chi-square sensitivity to large sample size. An ideal fit has χ^2/df of 1.0, however, values between 2 and 3 are acceptable, values less than 2 are desirable, and values greater than 5 are unacceptable (Byrne, 2001; Kline, 1998). Another fit index is the Root Mean Square Error of Approximation (RMSEA), which is a measure of goodness of fit if the model were estimated in the population rather than the sample. RMSEA is a measure that attempts to correct for large sample size and indicates the discrepancy in fit per degree of freedom. RMSEA values < .05 indicates good fit, values between .05 and .08 indicate acceptable fit, values between .09 and .10 indicate mediocre fit, and values greater than .10 indicate poor fit. The confidence interval (CI) should also be reported (Byrne, Maruyama, 1998). The absolute indices used in this study were the CMIN/df and RMSEA.

Relative fit indices. Relative fit indices determine how well a particular model explains a set of observed data compared with a range of other possible models. Measures in this category include the Tucker Lewis Index (TLI), and the Comparative Fit Index (CFI). The TLI compares alternative models rather than comparing one model with the null model. The TLI yields values that range from zero to one with values greater than .90 indicating good fit (Hu & Bentler, 1999). The CFI was developed to take sample size into account, which the Normed FIT Index (NFI) did not do (Bentler, 1990). Values of the CFI ranges from zero to one also, and a value of .95 or greater indicating good fit (Hu & Bentler). Both the TLI and the CFI were used in this study.

Parsimony. Parsimonious fit addresses how the model combines fit and parsimony. These fit indices assess parsimony of the models being compared. The RMSEA can also be use to test for parsimony because, as previously described it is expressed per degrees of freedom, making it sensitive to the number of estimated parameters in the model. Another index that is used to test for parsimony is the Akaike Information Criterion (AIC). The AIC is used in the comparison of two or more models, with smaller values representing a better-fit and greater parsimony(Akaike, 1987; Hu & Bentler, 1995). Parsimony was assessed in this study by RMSEA and the AIC.

Model Misspecification. A model could fit well in some areas, but be misspecified in others, yet provide evidence of overall satisfactory fit. It is therefore important that an assessment be done to identify any areas of misfit in the model. The standardized residual and modification indices provide information that helps to detect model misspecification. The residuals represent estimates of the number of standard deviations the observed residuals are from the zero residuals that would exist if the model fit were perfect. Values > ± 2.58 are considered to indicate discrepancy between the two variables, no residual were > ± 2.58 . Modification indices provide additional information about model fit, specifically, the extent to which the model is appropriately described. The modification Index (MI) is a χ^2 statistic with one degree of freedom. Along with the MI is an expected parameter change (EPC) value, which is provided in AMOS for each fixed parameter that is specified, which represents the expected drop in overall χ^2 value if the parameter were freely estimated in a subsequent run (Byrne, 2001).

Modification or Respecification of the Model.

Modification or respecification is done by the use of the modification indices, the modification index (MI) or the Lagrange Multiplier (LM) along with the expected parameter change (EPC) statistics. The MI is a special case of the LM. This allows the investigator to free or fix parameters and reevaluate the fit of the model. However, the possibility of a Type II error is increased as a result of many sequences of model modification (Kaplan, 1995). Model respecification is allowed in the model generating approach to SEM. This is done if any of the fit indices show inconsistencies between the data and the model. The new model corrects for external and internal specification errors found in the proposed model. Although, model respecification can be done statistically all modification decision were based on logical and theoretical considerations.

Summary.

In this chapter the population and sample were described. The empirical indicators for data collection along with relevant information on development, reliability, and validity were discussed. Data collection procedure and Human subject consideration were described. Preliminary data analysis was described, and finally, a description of the assessment of the overall model fit.

CHAPTER 5

RESULTS

The purpose of this study was to develop and test a model of a middle-range theory of quality of life in stroke survivors (TQOLSS) derived from King's (1981) Interacting Systems Framework for Nursing (ISFN). Eight hypotheses and two research questions were formulated. Testing included 1) evaluation of overall model fit, 2) examining the direct and indirect relationships between the variables, 3) determining the amount of variance in health-related quality of life (HRQOL) of stroke survivors accounted for by the model, and 4) examining the relationship between age, time since stroke and number of strokes and HRQOL.

The study findings are presented below. They are 1) structural model testing, and 2) testing of the study hypotheses and research questions.

Structural Model Testing

The initial structural model of the TQLOSS (Model A) that prescribes the relationships among the study variables was examined for model estimates and fit indices to identify improper solutions, hypothesized relationships, and model fit. The statistical Model A (Figure 5) was derived from the proposed theoretical model in Figure 4. This model was evaluated for overall fit using the previously described fit indices (χ^2 with df and corresponding p value, CMIN/df, TLI, CFI, and RMSEA). Analysis showed an overall fit for Model A : $\chi^2(11, N = 102) = 16.594$, $p < .001$, CMIN/df = 1.509, TLI = .75, CFI = .93, and RMSEA = .07 (CI .00-.136), which was not acceptable. Modification Indices indicated that a path from the number of strokes to perception of level of disability had an MI of 5.19 with an EPC of 9.4. This led to Model B.

Respecification of the model was based not only on statistical analysis but also on logical thinking. Number of strokes and perception of level of disability were moderately and significantly correlated (r =.28, p .01) suggesting that Impairments in the internal nervous system and functioning, tend to increase with the number of strokes. It is logical, therefore, to expect that changes in cognition and level of functioning will negatively affect perception of level of disability. Model B in Figure 6 is the respecified model based on the modification index, with the added a path from number of strokes to perception of level of disability. This respecified model was evaluated for overall fit. Analysis revealed an overall fit of Model B: χ^2 (10, N=102) = 10.989 p <. 001, CMIN/df = 1.099, TLI = .95, CFI = .98, RMSEA = .03 (CI .00-.12), indicating good fit and an AIC 62.989, suggesting the model was also parsimonious. The Akaike Information Criterion (AIC) value is considered to provide a relative ordering of models. The model with the lower AIC value is considered to provide a better description of the means of data than the model with a higher AIC value (Maruyama, 1998). Based on these analyses, and the fact that any additional re-specification would not be theoretically nor logically justified, Model B was accepted as the final structural model. In addition, Model B was used for hypothesis testing. Table 6 provides a comparison of the fit indices for Model A and Model B.

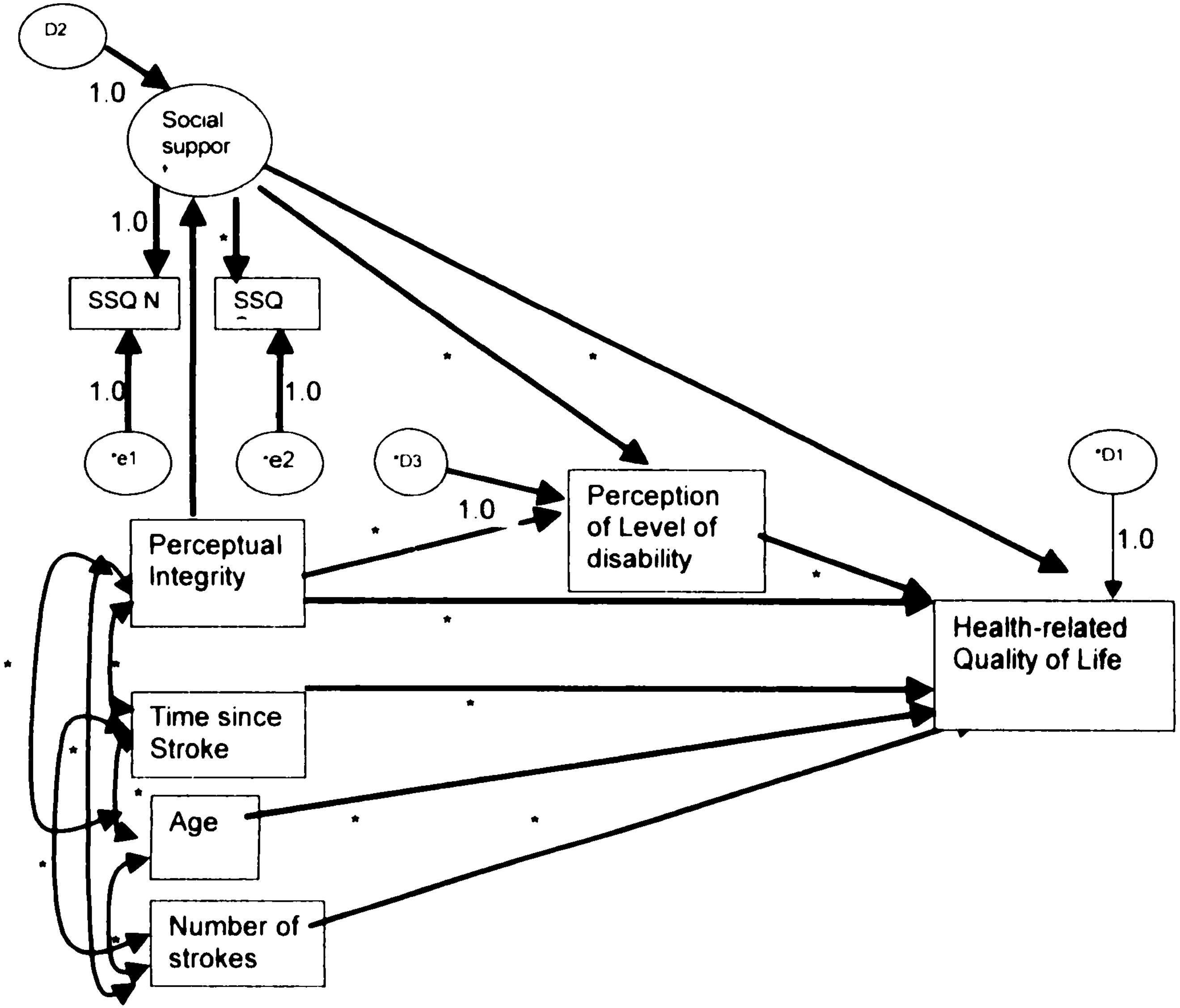


Figure 5

<u>Model A Full Structural Model of Theory of Quality of Life Of Stroke Survivors</u>

e = measurement error, D = disturbance (unexplained variance and errors), * = parameter estimates, → = direct effects, ↔ = correlation

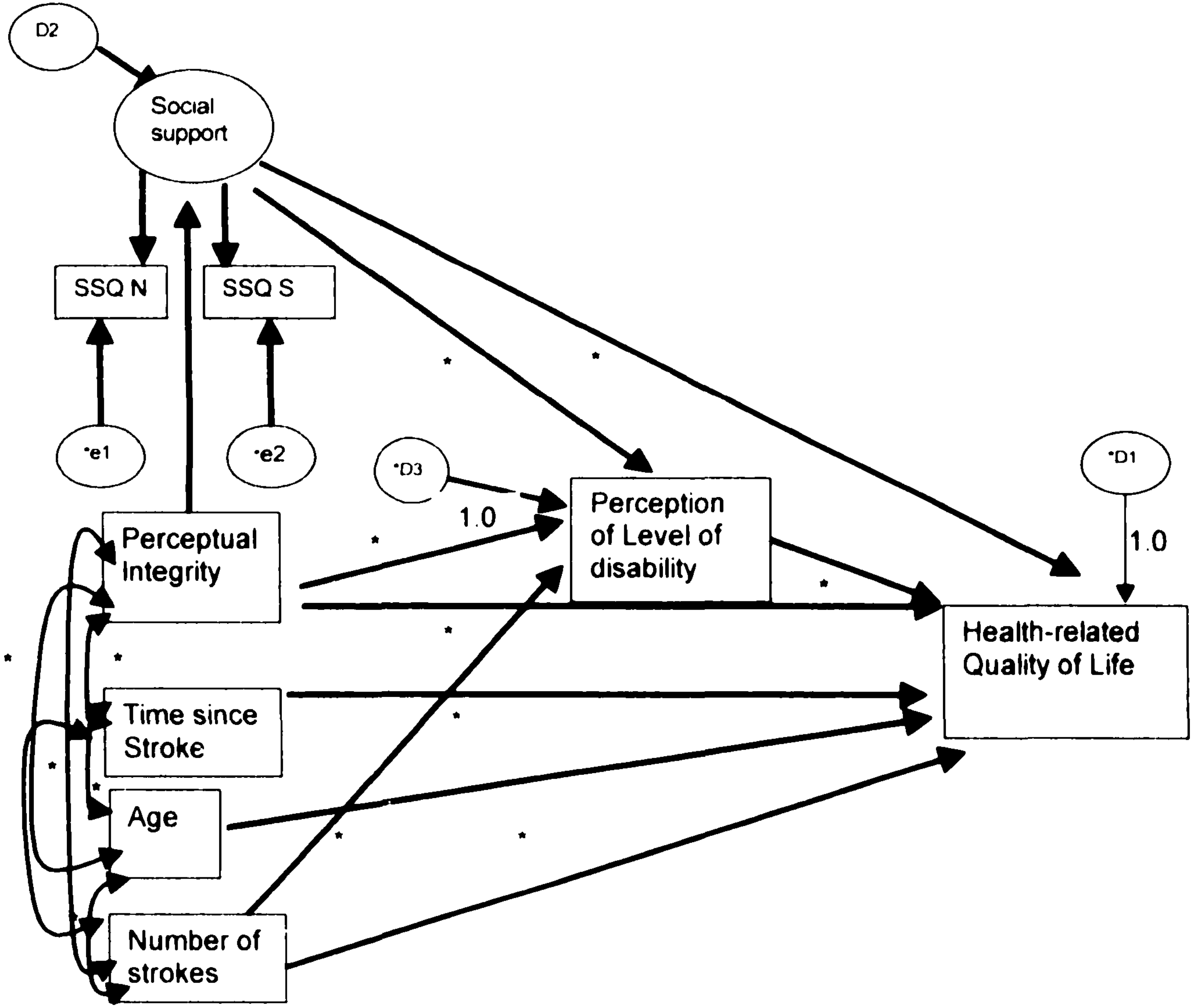


Figure 6

<u>Model B Alternative Full Structural Model of Theory of Quality of Life Of Stroke Survivors</u>
e = measurement error, D = disturbance (unexplained variance and errors), * = parameter estimates, - ▸ = direct effects, ◂ ▸ = correlation

Table 6

Fit Indices of Structural Models

Fit Index	Model A	Model B	Criteria
Chi square	16.594	10.989	Non significant or p > .05
Df (p value)	11 (< .001)	10 (< .001)	
CMIN/*df*	1.509	1.099	1 ideal fit, < 2 desirable, 2-3 acceptable, > 5 unacceptable
TLI	.75	.95	≥ .95
CFI	.93	.98	≥ .95
RMSEA	.07 (CI .00-36)	.03 (CI .00-.12)	< .05 good fit, .05-.08 acceptable fit, .09-10 poor fit
AIC	66.594	62.989	

CMIN/df = ratio of chi-square to degrees of freedom, TLI = Tucker Lewis Index, CFI = Comparative Fit Index, RMSEA = Root Mean Square Error of Approximation, AIC = Akaike Information Criterion.

Hypothesis Testing of the Theory of Quality of Life Of Stroke Survivors Model B

Figure 7 depicts the mapping of the hypothesized relationships with path coefficients for the TQLOSS Model B. The results of hypothesis testing follow.

Hypothesis 1 which proposed that perceptual integrity (cognition) has a direct and positive effect on social support was not supported. The path coefficient $\beta = .22$ was positive, but not significant.

Hypothesis 2 which proposed that perceptual integrity (cognition) has a direct and negative effect on perception of level of disability was supported. The path coefficient $\beta = .21$, $p < .05$ was significant and in the direction predicted.

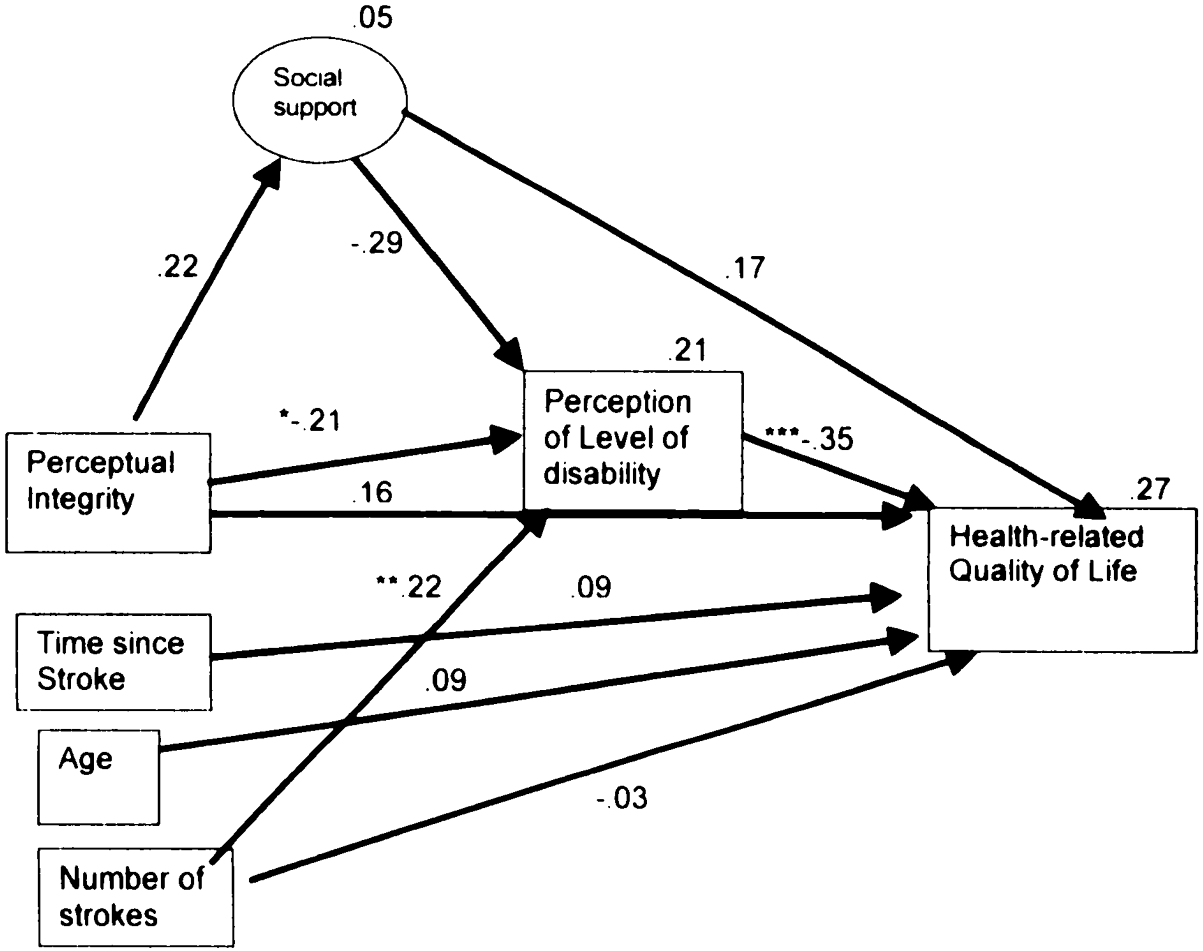


Figure 7
Hypothesized Paths Theory of Quality of Life Of Stroke Survivors Model B
Standardized path coefficients and squared multiple correlations are shown.
* = p<.05, ** = p<.01, *** = p<.001

Hypothesis 3 which proposed that perceptual integrity (cognition) has a direct and positive effect on the stroke survivor's health-related quality of life (HRQOL) was not supported. The path coefficient $\beta = .16$ was in the predicted direction but was not significant.

Hypothesis 4 which proposed that perceptual integrity (cognition) has an indirect effect on the stroke survivor's HRQOL through perception of level of disability was supported. The component path coefficient ($\beta = -.21$, $p < .05$) for the effect of cognition on perception of level of disability was negative and significant, and the component path coefficient ($\beta = -.35$, $p < .001$) for the effect of perception of level of disability on HRQOL was negative and significant; indicating an indirect effect of cognition on HRQOL through perception of level of disability.

Hypothesis 5 which proposed that perceptual integrity (cognition) has an indirect effect on the stroke survivor's HRQOL through social support was not supported. The component path coefficient ($\beta = .22$, $p > .05$) for the effect of cognition on social support was not significant, and the component path coefficient ($\beta = .17$, $p > .05$) for social support on HRQOL was not significant.

Hypothesis 6 which proposed that perception of level of disability would have a direct and negative effect on the stroke survivor's HRQOL was supported. The path coefficient $\beta = -.35$, $p < .001$ was significant and in the predicted direction.

Hypothesis 7 which proposed that social support would have a direct and positive effect on the stroke survivor's HRQOL was not supported. The path coefficient $\beta = .17$ was positive but not significant.

Hypothesis 8 which proposed that social support would have a direct and negative effect on perception of level of disability was not supported. The path coefficient $\beta = -.29$, $p > .05$ was in the predicted direction but not significant.

Research Question 1 asked "How much of the variance in HRQOL is explained by the model? Twenty seven percent (27%) of the variance in HRQOL of stroke survivors was explained by the respecified model (Model B). However, only three of the six predictor variables in the model (cognition, perception of level of disability, and number of strokes) accounted for the variance.

Research Question 2 asked "What is the relationship among age, time since stroke, and number of strokes to the HRQOL of stroke survivors? Age and time since stroke were not significantly related to HRQOL (β = .09, $p > .05$ for both). However, there was a direct and positive effect of number of strokes on the perception of level of disability (β = .22, $p < .01$). There was also an indirect effect of number of strokes on the HRQOL of the strokes survivor through perception of disability, both the component path for the effect of number of strokes on perception of level of disability and the component path for the effect of perception of level of disability on HRQOL were significant.

Summary of Analysis

In this chapter a report of the results for modeling and hypotheses testing is provided. The initial model (Model A) that was proposed did not have an acceptable fit, however, an alternative model (Model B) based on the modification indices was respecified and tested, and showed a good fit. The hypothesized relationships between cognition and perception of disability (Hypothesis 2), cognition and HRQOL mediated by perception of level of disability (Hypothesis 4), and perception of level of disability and HRQOL (Hypothesis 6) were supported. However, the proposed relationships among cognition and social support (Hypothesis 1), cognition and HRQOL (Hypothesis 3), cognition and HRQOL through social support (Hypothesis 5), social support and HRQOL (Hypothesis 7), and social support and perception of level of disability (Hypothesis 8) were not supported. Three of the six-predictor factors (cognition, perception of level of disability, and number of strokes) accounted for twenty seven percent (27%) of the variance in the respecified model (Model B) of the Theory of Quality of Life Of Stroke Survivors.

CHAPTER 6

DISCUSSION

The purpose of this study was to test a middle range theory of quality of life in stroke survivors (TQLOSS) derived from King's (1981) conceptual framework using a stroke specific quality of life instrument. A descriptive correlational study was conducted with 102 stroke survivors attending one of two clinics affiliated with an urban university in a large southeastern Michigan City with a predominantly African American population. The proposed model was tested, re-specified, and the respecified model was tested using structural equation modeling.

The theoretical framework for this study was King's (1981) conceptual framework for nursing. A major focus of King's framework is the health of individuals, a function of their interaction with the environment. Health is the ability of the individual to function in their usual roles, and the performance of ADLs in a manner that allows them to lead a relatively useful, satisfying, productive, and happy life. Health-related quality of life (HRQOL) is the individual's perceptions of performance in the domains of physical, psychological, social, spiritual, and role functioning as well as general well-being in relation to illness.

This study focused on the relationships among perceptual integrity (cognition), social support, perception of level of disability, and health-related quality of life of stroke survivors derived from King's (1981) concepts of perception, interaction, self, and health, which are rather abstract and difficult to measure at the grand theory level. Theoretical perspectives and empirical findings from nursing and other literature were reviewed to provide more focused definitions of the concepts that are consistent with King's conceptualizations. Theoretical and operational definitions of the concepts were identified. A discussion of the findings will be presented in relationship to the following

1) Findings, 2) Implications for theory, 3) Implications for research, 4) Implications for practice, 3) Strengths and limitations, and 4) Conclusions.

Discussion of Findings

Overall, the respecified structural model of the theory of quality of life of stroke survivors (TQLOSS) had a good fit and accounted for 27% of the variance in HRQOL. Thus supporting the proposed relationships among perceptual integrity (cognition), social support, perception of level of disability, health-related quality of life, age, time since stroke and number of strokes in the theory or quality of life of stroke survivors (TQLOSS). The significant relationships between perceptual integrity (cognition) and perception of level of disability, cognition and the stroke survivor's HRQOL through perception of level of disability, and perception of level of disability and quality of life provides new information on the importance and role of perception in HRQOL. This investigator is not aware of any studies that focused on the relationship of cognition and perception of level of disability, perception of level of disability and HRQOL, nor of other studies of HRQOL of stroke survivors that examined perception of level of disability as a possible predictor.

The individual's perception of disability is based on and influenced by the integrity of their perceptual system or cognition. The structural impairments that may lead to alteration in cognition may be mild to severe. The changes in perception could be slight, and/or not obvious to others. These changes can affect the individuals sense of self, their assessment of their level of disability and quality of life.

King (1981) argues that self is dynamic with values and beliefs, is perceived in relations to others, and objects in the environment; and that health is a function of persons interacting with their environments to be able to perform ADLs, function in their usual roles, and lead a useful, satisfying, productive and happy life. The definition of self then becomes important in assessing one's level of health. Easton (2001) found that stroke survivors go through a process of recovery that includes "blending", which involves building a new life and going on. In this phase, they may express feelings of "health and well-being" again (p. 105). Buscherof (1998) a nurse who is a stroke survivor talked about the development of an accurate body image and a cumulative building of self-confidence, self-esteem, and a sense of competence in the development of a new sense-of-self and the relationship to QOL poststroke. According to life transition theory, the individual goes through a process that bridges from the reality that has been disrupted to a newly constructed or surfacing reality. The emerging reality integrates the event in such a way that the sense of self is maintained intact. The purpose is to create new meaning in one's life when the old meanings have been fractured (Selder, 1989). The stroke survivor's new sense of self is their reality, which gives meaning to everything in their life, including the meaning of health.

Most studies of stroke survivors level of disability have been based on functionality (Glass & Maddox, 1992; Glass et. al., 1993, Lindmark & Hamrin, 1995). However, qualitative studies have shown that the stroke survivors experience in terms of the meaning of the loss of function was more important than the actual loss (Doolittle, 1991; Folden, 1994; Mumma, 1986; Secrest & Thomas, 1999; Jongbloed, 1994). Neimi et al (1988) reported that the survivors subjective experience of disability and insufficiency was the most important variable related to deterioration in QOL. Clearly, it is the individual's perception that is important, not someone else' s assessment, and not based on a checklist or scale. The foregoing underscores the importance of the individual's assessment of their perception of level of disability in relation to HRQOL.

Hypothesized relationships between perceptual integrity (cognition) and social support, cognition and HRQOL of the stroke survivor, cognition and HRQOL of the stroke survivor through social support, social support and perception of level of disability, and social support and HRQOL were not supported. This was somewhat surprising given the extensive theoretical and empirical support for the proposed formulations. Findings from other studies that reported significant relationships between the hypothesized relationships will be discussed along with possible reason for lack of significant findings in this study.

King (1981) indicated that interaction involves the exchange of materials goods and/or services and that interaction is essential to the growth of relationships. Interactions may therefore have either positive or negative influences on health. Social support is conceptualized as human interaction based on King's framework. Social support has been reported to have a generalized beneficial effect on overall well-being irrespective of whether the persons are under stress (main- or direct-effect model) or a protective effect (buffering model) for persons under stress (Cohen & Willis, 1985). Many researchers reported that social support was a significant predictor of QOL/Subjective Well-Being/Life Satisfaction (Aström et. al., 1992; Kim et. al., 1998; King, 1996; Löfgren et. al., 1999; Viitanen et. al., 1988; Wyller, Holmen et. al., 1998; Yoon, 1997).

The lack of support for the hypothesized relationship between cognition and social support, cognition and HRQOL mediated by social support, and social support and perception of level of disability may be due to the instrument used to measure social support. Lack of adequate instrumentation for complex constructs is problematic for researchers. The SSQSR measures perceived social support in broad terms such a "whom can you really count on to be dependable when you need help", rather than asking "whom could you count on to be dependable when you need help with transportation to the clinic/grocery store, or assistance with ADLs", specific types of help the stroke survivor may need. A social support instrument specifically designed to measure the social supports of stroke survivors might have resulted in different findings.

The participants in this study were predominantly African Americans (81%). African Americans have been underrepresented in quality of life stroke research to date.

The ethnicity of the sample was not indicated (in the European studies and the American studies by Kim et al., 1999 and Bethoux et al., 1999) or ranged from 8% (Duncan et al., 1997), to a high of 22% (King, 1996). The relationship between ethnicity and quality of life (QOL) was not examined in any of the studies reviewed. QOL was not found to be significantly different between whites and non-whites on the total SS-QOL scores nor in eleven of the Subscale (domain) scores. Whites reported significantly higher levels of QOL in the social roles domain than non-whites, and those with a higher level of education reported higher levels of QOL in the social roles domain. The between group difference in QOL social roles domain based on ethnicity persisted after controlling for education. This difference may be explained by anecdotal findings that indicated that African Americans tend not to participate in social activities if they are unable to maintain their "image".

Three of the participants reported that their overall quality of life was better than before the stroke but would rate it as the same since there was not a "better than before the stroke" choice. They attributed their improved quality of life with reordering their priorities, especially their relationship with God. Seventy percent (70%) of the participants reported that they participated in religious activities. The church, although it provides less support than the family for the older African American, has been reported to contribute to feelings of well-being (Walls, 1992).

Implications for Theory

This study contributes to the growing number of middle range theories derived from King's (1981) conceptual framework for nursing. The empirical support for the conceptualizations in this study provided credibility for King's conceptual framework, thus making a substantive contribution to the advancement of a recognized nursing theory (Fawcett, 1989). When nurse researchers use nursing conceptual frameworks/theories to do nursing research they contribute to the science of nursing by adding to the knowledge base.

The development and testing of theories derived from conceptual frameworks and grand theories builds the knowledge base for nursing, provides evidence of credibility for one of nursing's grand level theories, gives direction for future research, and can be used to develop nursing interventions. Nursing interventions based on research provides evidence for the validity and efficacy of the intervention. This would lead to the development of practice theories that are conceptually based and empirically tested.

The findings of this study, while partially supporting the hypothesized relationships, indicate a need to provide a better explanatory model of quality of life of stroke survivors for the further advancement of nursing science. The model needs to be refined to identify other moderator/mediator variables and retested. The identification of other variables and patterns of direct and indirect influences will better the understanding of the phenomenon of quality of life of stroke survivors. Some of these factors might be educational level and religiosity. It is possible that perception of level of disability may have a direct effect on social support rather than social support affecting perception of level of disability as proposed in the TQLOSS. The relationship between these two variables may be reciprocal which would then make the TQLOSS a nonrecursive rather than recursive model. This would require a very different analytic technique. A study using the same model and a different measurement of social support needs to be done. The foregoing recommendations will further the advancement of nursing science by providing an explanatory theory for quality of life of strokes survivors.

Implications for Research

In addition to model expansion, future research needs to include replication in the same population but with a larger sample and replication in other populations. This would allow for greater generalizability. A longitudinal design, to assess changes in the variables and therefore allow one to infer causation. An interventional research study is also recommended, as it would be low risk to initiate. Perception of level disability demonstrated strong effects on the HRQOL of stroke survivors. Therefore, an intervention program that used strategies to enhance the individual's perception of level of disability must be developed and tested.

Implications for Practice

The findings relative to the relationship of perception of disability as a strong predictor of HRQOL of stroke survivors warrants consideration by clinicians. Assessment of the stroke survivors perception of their level of disability using a Visual Analog Scale can provide the clinician with a subjective evaluation of the individuals status, which can then be compared with an objective evaluation (level of functionality) by the clinicians. An assessment of the individual's subjective rating of their HRQOL using the SS-QOL, which takes about ten to fifteen minutes to administer, would provide the clinician information related to the areas that were low in their HRQOL. The information from the VAS and the SS-QOL could then be used to develop strategies to assist the stroke survivor and their family/caregivers to enhance the stroke survivors sense of self and the QOL of the stroke survivor and the family/caregivers.

Strengths and Limitations

The strengths of this study are related to the development and testing of a middle range theory of quality of life in a predominantly African American population. The theoretical framework for this study was King's (198) conceptual framework for nursing. A major focus of King's framework is the health of individuals and groups and how each is influenced by interaction with the environment. From King's perspective, knowledge about human environment interactions in relation to health serves as the basis of professional nursing. The grand theories of nursing provide a conceptual framework for the development and testing of middle-range and micro theories. The use of substruction as a method for development of a middle range theory was also a strength of this study. These middle-range and micro theories can provide the basis for nursing assessment and intervention.

Another strength of this study is that it is novel in that it is innovative work in the theoretical area of relating cognition, social support, perception of level of disability, and health-related quality of life (HRQOL) of stroke survivors. This study brings a needed dimension of explanation about the relationships between personal and interpersonal features of nursing situations in relation to patient outcomes. There are no other studies known to this researcher that used a nursing theoretical framework to examine predictors of HRQOL of stroke survivors.

It is also the only study known to this researcher that used perception of level of disability, a subjective measure, as a predictor of HRQOL of stroke survivors. The individual's sense of self provides their reality, therefore, the assessment of the perception of level of disability, which was derived from King's concept of self, and its relationship to HRQOL of stroke survivors is appropriate and necessary. This brings a personal meaning versus self-evaluation of function to the understanding of quality of life of the stroke survivor.

An additional strength is the use of an advanced statistical technique for theory testing, critical to get beyond bivariate correlations. SEM ensures that the most advanced statistical techniques are employed in the analysis of the theoretical model. SEM also provides the most precise and reliable estimations of all hypothesized relationships. The use of SEM provides a means to parsimoniously develop and test theory, one of the most critical endeavors in nursing. According to Boyd et. al.(1988) nurses frequently work with complex, theoretical constructs, which demand multiple variables and hypotheses. SEM allows the researcher to use and test these complex constructs and their equally complex relationships. Thus, SEM is a valuable technique for nurse researchers.

The cross-sectional design of the study is a limitation. It is controversial to make statements of cause and effect relationships without using either an experimental or prospective, longitudinal design. The use of a longitudinal design would allow one to answer questions related to the role of social support over time and its affect on perception of level of disability and HRQOL; the affect of changes in cognition on perception of level of disability and HRQOL. It is possible that perception of level of disability is a predictor of the individual's social support as well as social support being a predictor of perception of disability. This reciprocal relationship cannot be determined unequivocally using a cross-sectional design.

As discussed previously, this study had 102 subjects, which is considered a small sample size. which was adequate for statistical stability (Kline, 1988). An overall good fit was obtained, however, it may have lacked sufficient power to fully explain all the hypothesized relationships and account for the nonsignificant paths.

While the generalizability of the study findings may be somewhat limited. These findings can be generalized to the population from which the sample was taken, and urban African Americans. However, the purpose of this study was to test a model of a theory of quality of life in stroke survivors and by replication of the study in other populations to be able to generalize the theory to stroke survivors.

Conclusion

This theory driven study tested a middle range theory of health-related quality of life in stroke survivors using a stroke specific quality of life measure. The middle range theory derived from King's (1981) conceptual framework reconceptualized health as health-related quality of life and purported the relationships of cognition, social support, perception of level of disability and health-related quality of life in stroke survivors. The model clearly demonstrated the importance of one's perception of level of disability as a significant predictor, and mediator of cognition as a predictor, of quality of life of stroke survivors. The findings provide empirical evidence for the theory of quality of life of stroke survivors, which lends credibility to King's conceptual framework. Although the hypotheses regarding the relationship between cognition and social support, social support and perception of level of disability, and social support and health-related quality of life were not supported, the discussion provided suggestions to account for the nonsignificant findings. Recommendations were made for future research in the area of theory development and research methodology. Information that can be used by the clinicians caring for stroke survivors was presented.

APPENDIX A

MEASURES

Appendix A 1

Demographic Questionnaire

Identification Code______ Date_______________

Date of Birth_____________________

Date of Stroke_____________________

Female____ Male____

Ethnic Background
- African-American____
- Asian____
- Caucasian____
- Hispanic____
- Native American____
- Other (Specify)__________

Present marital status
- Married____
- Single____
- Separated____
- Divorced____
- Widowed____
- Living with significant other____

Religious Preference
- Catholic_____
- Jewish_____
- Muslim____
- Protestant____
- None____
- Other (Specify) _____________

Participation in religious activities
- Regular (weekly) _____
- Occasional participation (about monthly) _____
- Infrequent participation (1-2 times a year) ____
- Inactive ____

Living conditions
- Live alone____
- Live with spouse/significant other___
- Live with daughter/son_____
- Live with a friend____
- Other (specify) ________________

Are you employed now?
- Yes___ Hours per week___
- No___ Retired___
- Disabled___

What is the highest grade of school that you completed?

Grade School	High School	College	Graduate School
1 2 3 4 5 6 7 8	9 10 11 12	1 2 3 4	5 6 7 8 9 10 11 12

Do you belong to the Spice of Life Club (at RIM) Yes___ No____
How long have you been a member______

Appendix A 2

SOCIAL SUPPORT QUESTIONNAIRE -SHORT FORM

SSQSR

INSTRUCTIONS:

The following questions ask about people in your environment who provide you with help or support. Each questions has two parts. For the first part, list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Give the person's initials and their relationship to you (see example). **Do not list more than one person next to each of the letters beneath the question.**

For the second part, circle how **satisfied** you are with the overall support you have.

If you have no support for a question, check the words "**No one,**" but still rate your level of satisfaction. Do not list more than nine persons per question.

Please answer all questions as best you can.

EXAMPLE:

Who do you know whom you can trust with information that could get you in trouble?

No one
1) T.N. (brother)
2) L.M. (friend)
3) R.S. (friend)
4) T.N. (father)
5) L.M. (employer)
6)
7)
8)
9)

How Satisfied?

6 - very satisfied
5 – fairly satisfied
4 – a little satisfied
3 – a little dissatisfied
2- fairly dissatisfied
1- very dissatisfied

1 Whom can you really count on to be dependable when you need help?

No one 1) 4) 7)
2) 5) 8)
3) 6) 9)

2. How satisfied?

6 - very satisfied	5 – fairly satisfied	4 – a little satisfied	3 – a little dissatisfied	2- fairly dissatisfied	1- very dissatisfied

3. Whom can you really count on to help you feel more relaxed when you are under pressure or tense?

No one 1) 4) 7)
2) 5) 8)
3) 6) 9)

4. How satisfied?

6 - very satisfied	5 – fairly satisfied	4 – a little satisfied	3 – a little dissatisfied	2- fairly dissatisfied	1- very dissatisfied

5. Who accepts you totally, including both your worst and your best points?

No one 1) 4) 7)
2) 5) 8)
3) 6) 9)

6. How satisfied?

6 - very satisfied	5 – fairly satisfied	4 – a little satisfied	3 – a little dissatisfied	2- fairly dissatisfied	1- very dissatisfied

7. Whom can you really count on to care about you, regardless of what is happening to you?

No one 1) 4) 7)
2) 5) 8)
3) 6) 9)

8. How satisfied?

6 - very satisfied	5 – fairly satisfied	4 – a little satisfied	3 – a little dissatisfied	2- fairly dissatisfied	1- very dissatisfied

9. Whom can you really count on to help you feel better when you are feeling generally down-in-the-dumps?

No one	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

10. How satisfied?

6 - very satisfied	5 – fairly satisfied	4 – a little satisfied	3 – a little dissatisfied	2- fairly dissatisfied	1- very dissatisfied

11. Whom can you count on to console you when you are very upset?

No one	1)	4)	7)
	2)	5)	8)
	3)	6)	9)

12. How satisfied?

6 - very satisfied	5 – fairly satisfied	4 – a little satisfied	3 – a little dissatisfied	2- fairly dissatisfied	1- very dissatisfied

Sarason, Sarason, Shearin, & Pierce, 1987

Appendix A 3

Functional Independence Measure (FIM)

Cognitive Subscales

Communication

Comprehension ______
_____Auditory
_____Visual
_____ Both

Expression ______
_____Vocal
_____Nonvocal
_____ Both

Social Cognition

Social Interaction ______

Problem Solving ______

Memory ______

Cognitive Subtotal Score ______

FIM Levels

NO HELPER

7 Complete Independence
(Timely, Safety)
6 Modified Independence
(Device)

HELPER

Modified Dependence

5 Supervision
4 Minimal Assistance
(Subject = 75% +)
3 Moderate Assistance
(Subject = 50% +)

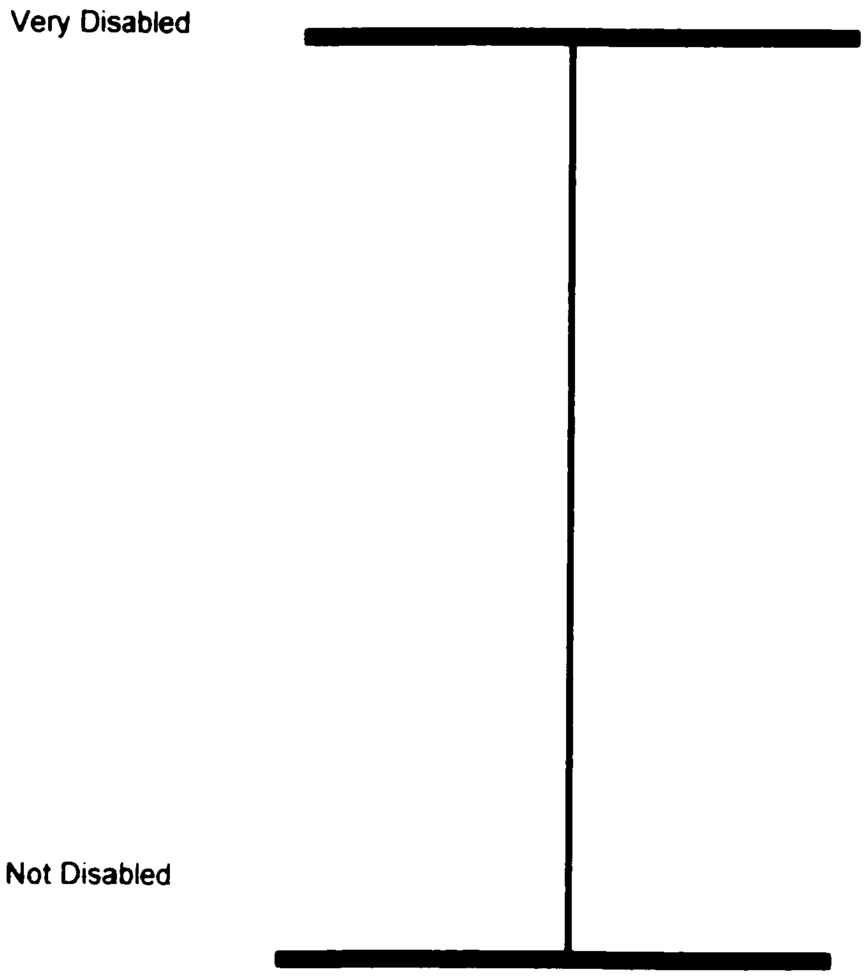
COMPLETE DEPENDENCE

2 Maximal Assistance
(Subject = 25% +)
1 Total Assistance
(Subject = 0% +)

UDS Data Management Service, SUNY Buffalo, 1996

Appendix A 4

Visual Analog Scale



Appendix A 5

Stroke-Specific Quality of Life (SS-QOL)

DURING THE PAST WEEK

	Couldn't do it at all	A lot of Trouble	Some trouble	A little trouble	No trouble at all
SC1. Did you need help preparing food?					
SC2. Did you need help eating, for example, cutting food or swallowing?					
SC4. Did you need help getting dressed, for example, putting on socks or shoes, buttoning buttons, or zipping?					
SC5. Did you have trouble taking a bath or shower?					
SC8. Did you have trouble using the toilet?					
VI. Did you have trouble seeing the television well enough to a show?					
V2. Did you have trouble reaching for things because of poor eyesight?					
V3. Did you have trouble seeing things off to one side?					
L2. Did you have trouble speaking, for example, need to use gestures or pointing?					
L3. Did you have trouble speaking, for example, get stuck, stutter, stammer, or slur your words?					
L5. Did other people have trouble understanding what you said?					
L6. Did you have trouble finding the word you wanted to say?					
L7. Did you have to repeat yourself so others could understand you?					

	Couldn't do it at all	A lot of Trouble	Some trouble	A little trouble	No trouble at all
M1. Did you have trouble walking? (If client can't walk, circle 1 and go to M7)					
M4. Did you lose your balance when bending over or reaching for something?					
M6. Did you have trouble climbing stairs?					
M7. Did you have to stop and rest more than you would like when walking or using the wheelchair?					
M8. Did you have trouble with standing?					
M9 Did you have trouble getting out of a chair?					
W1. Did you have trouble doing daily work around the house?					
W2. Did you have trouble finishing jobs that you started?					
W3. Did you have trouble doing the work you used to do?					
UE1. Did you have trouble writing or typing?					
UE2. Did you have trouble putting on socks?					
UE3. Did you have trouble buttoning buttons?					
UE5. Did you have trouble zipping a zipper?					
UE6. Did you have trouble opening a jar?					
SR4. I did my hobbies and recreation for shorter periods of time than I would like.					
SR5. I didn't see as many of my friends a I would like.					

DURING THE PAST WEEK

	Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
T2. It was hard for me to concentrate.					
T3. I had trouble remembering things.					
T4. I had to write things down to remember.					
P1. I was irritable.					
P2. I was impatient with others.					
P3. I am not the same person I used to be.					
MD2. I was discouraged about my future.					
MD3. I wasn't interested in other people or activities					
MD6. I felt withdrawn from other people.					
MD7. I had little confidence in myself.					
MD8. I was not interested in food.					
FR5. I didn't join in activities just for fun with my family.					
FR7. I felt I was a burden to my family.					
FR8. My physical condition interfered with my family life.					
SR1. I didn't go out as often as I would like					
SR 6. I had sex less often than I would like.					
R7. My physical condition interfered with my social life.					
E2. I felt tired most of the time.					
E3. I had to stop and rest often during the day.					
E4. I was too tired to do what I wanted to do.					

DURING THE PAST WEEK

	A lot worse than before the stroke	Somewhat worse than before the stroke	A little worse than before the stroke	The same as before the stroke
1E. My energy level is				
2L. My speech is				
3M. My walking is				
4V. My vision is				
5UE. The use of my arms or hands is				
6T. My thinking is				
7MD. My mood is				
8P. My personality is				
9W. I do my jobs at home or at work				
10SC. I can take care of myself				
11FR. I do things for my family				
12SR. I do things for my friends				
13. Overall my quality of life is				

Williams, Weinberger, Harris, & Biller, 1999

APPENDIX B

WSU Human Investigation Committee Approval and Consent Form

WAYNE STATE UNIVERSITY

HUMAN INVESTIGATION COMMITTEE
4201 St. Antoine Blvd . UHC 6-G
Detroit, Michigan 48201
Phone: (313) 577-1628
Fax: (313) 993-7122
HIC Website: www.orsps.wayne.edu

NOTICE OF EXPEDITED APPROVAL

TO: **Jenecia Fairfax**
(Nursing)
[redacted]
Detroit, 48207

FROM: Peter A. Lichtenberg, Ph.D. [redacted]
Chairman, Behavioral Institutional Review Board (B03)

DATE: July 3, 2001

RE: Protocol # 06-68-01(B03)-ER "Theory of Quality of Life of Stroke Survivors" Source of Funding: King/Chavez/Parks Future Faculty Dissertation Award

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The above-referenced Protocol and Informed Consent were **APPROVED** following Expedited Review (Category 7*) by the Chairman for the Wayne State University Institutional Review Board (B03) for the period of **July 3, 2001 through July 2, 2002.**

EXPIRATION DATE: July 2, 2002

This approval does not replace any departmental or other approvals that may be required.

Federal regulations require that all research be reviewed at least annually. **It is the Principal Investigator's responsibility to obtain review and continued approval before the expiration date.** You may not continue any research activity beyond the expiration date without HIC approval.

- If you wish to have your protocol approved for continuation after the above approval period, please submit a completed Continuation Form at least six weeks before the expiration date. It may take up to six weeks from the time of submission to the time of approval to process your continuation request.
  Failure to receive approval for continuation before the expiration date will result in the automatic suspension of the approval of this protocol on the expiration date. Information collected following suspension is unapproved research and can never be reported or published as research data.
- If you do not wish continued approval, please submit a completed Closure Form when the study is terminated.

All changes or amendments to your protocol or consent form require review and approval by the Human Investigation Committee (HIC) **BEFORE** implementation.

You are also required to submit a written description of any adverse reactions or unexpected events on the appropriate form (Adverse Reaction and Unexpected Event Form) within the specified time frame (see HIC policy).

- **Based on the Expedited Review List, revised November, 1998**
- **Stephen Cavanagh, Ph.D., RN,** Assoc Dean for Academic and Clinical Affairs, [redacted].

Revised 1/99

Title: Theory of quality of life of stroke survivors

Principal Investigator- Jenecia Fairfax, MSN, RN

"Behavioral" Research Informed Consent

A **Introduction and Purpose:**

I am being asked to take part in this research study to see what things affect the quality of life of stroke survivors. The study is being done by Jenecia Fairfax a doctoral student at the College of Nursing at Wayne State University.

B **Procedure:**

If I take part in this study, I will be asked to answer a series of questions, which will take about one hour, one time only. I can have the questions read to me by the investigator/research assistant and my answers recorded, or I may complete them myself. I may refuse to answer any question that is upsetting to me. I will be asked questions about my supports and how I have been since the stroke.

C **Benefits:**

There may be no direct benefit to me; however, information from this study may benefit other subjects in the future.

D **Risks:**

By taking part in this study, I may feel anxious or sad in answering questions about my supports and effects of the stroke.

E **Alternatives:**

I can choose not to participate.

F **Voluntary Participation/Withdrawal:**

Taking part in this study is voluntary. I may choose not to take part in this study, or if I decide to take part, I can later change my mind and withdraw from the study. My decision will not change the present or future health care or other services that I receive.

G **Costs:**

There is no cost to me for taking part in this study.

H **Compensation:**

In the unlikely event that I become injured as a result of taking part in this study, treatment will be offered to me, or I will be given information about where to receive medical care; but I or my insurance company will be responsible for the costs. No reimbursement, compensation or free medical care is offered by Wayne State University or the Detroit Medical Center. For taking part in this study, I will receive a gift certificate to a local retail store as a "thank you" for my time.

Title: Theory of quality of life of stroke survivors

I Confidentiality:

All information collected about me during the course of this study will be kept confidential to the extent permitted by law. I will be identified in the research records by a code number. Information, which identifies me personally, will not be released without my written permission, however, my records may be reviewed by the study sponsor, its agents, the Wayne State University Human Investigation Committee, and appropriate federal agencies. Information from this study may be published, but my identity will be kept confidential in any publications.

J Questions:

This study has been explained to me and all of my questions have been answered. If I have any questions in the future or in the case of a research related injury or illness, I may contact Jenecia Fairfax (Principal Investigator) at [redacted]. If I have any questions about my rights as a research subject, the Chair of the Human Investigation Committee can be contacted at [redacted].

K Consent to Participate in a Research Trial:

To voluntarily agree to take part in this study, I must sign on the line below. If I choose to take part in this study, I may withdraw at any time. I am not giving up any of my legal rights by signing this form. My signature below indicates that I have read, or had read to me, this entire consent form, including the risks and benefits, and have had all my questions answered. I will be given a copy of this consent form.

Signature of Study Subject ____________________ Date ____________

Printed Name of Study Subject/Patient ____________________ Date ____________

Signature of Legally Authorized Representative ____________________ Date ____________

Relationship to Subject ____________________

Signature of Witness ____________________ Date ____________

Signature of Investigator/Designee Obtaining Informed Consent ____________________ Date ____________

APPROVED

JUL 0 3 2001

WAYNE STATE UNIVERSITY
MEDICAL INVESTIGATION COMMITTEE

Request for Participation
(Original)

[redacted]
Detroit MI 48207

Date____________

Dear____________________________

My name is Jenecia Fairfax. I am a nurse working on my doctorate at Wayne State University. I am doing research about stroke survivors. The purpose of this study is to learn about the factors that contribute to the quality of life after a stroke. You have been identified as a possible research participant.

I will be calling you within a week of your receiving this letter to determine your willingness to participate in this study. If you agree to participate, I will meet with you at your convenience at home or at the clinic during your follow-up visit. Information about this study can be obtained from Jenecia Fairfax at [redacted].

Thank you,

Jenecia Fairfax, MSN, RN

WAYNE STATE
UNIVERSITY

HUMAN INVESTIGATION COMMITTEE
4201 St Antoine Boulevard - UHC-6G,
Detroit Michigan 48201
Phone: (313) 577-1628
FAX: (313) 993-7122
HIC Website: www.hic.wayne.edu

Notice of Expedited Amendment Approval

To: Jenecia Fairfax
(Nursing)
[redacted]
Detroit, MI 48207

From: Peter A. Lichtenberg, Ph.D.
Chairman, Behavioral Institutional Review Board (B03)

Date: July 31, 2001

RE: **Expedited Amendment to Protocol #:** 06-68-01(B03)-ER "Theory of Quality of Life of Stroke Survivors" Source of Funding: King/Chavez/Parks Future Faculty Dissertation Award

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The following requested change(s) to the above-referenced protocol have been **APPROVED** following **expedited review**, and are effective immediately.

- Receipt of a PI-initiated amendment to the Protocol (Inclusion criteria changed to include southeastern Michigan and treated at WSU/DMC Stroke Program Clinic or RIM Clinic, age changed to >50, time since stroke changed to at least 4 months post stroke) and Other (Participation Letter changed to include new contact information). All items submitted on behalf of the PI on **July 30, 2001.**

This protocol, as amended, will be subject to annual review by **July 2, 2002.**

WAYNE STATE UNIVERSITY

Wayne State University
Human Investigation Committee

Medical/Behavioral Amendment Form

University Health Center, 6G
4201 St. Antoine Blvd.
Detroit, MI 48201
[redacted]

All Submissions must be in standard type.

Section A: Principal Investigator (PI)

1. Name of PI: Jenecia Fairfax PI's Signature [redacted]
2. Mailing Address [redacted]
Detroit MI 48207 Telephone: 313-567-2260
Pager #:
Department: E-mail jfras41@aol.com
3 Form Completed by: Jenecia Fairfax Signature
(Print Name)
4. Telephone: [redacted] Date Form Completed: July 30, 2001
5. Source of Funding: King/Chavez/Parks Future Faculty Dissertation Award
6.

Section B: Protocol Information

7. **HIC Protocol Number**: 06-68-01(B03)-ER
8. Project Title: "Theory of quality of life of Stroke Survivors"
9. Date of First Approval: July 3, 2002 Date of Last Continuation Approval N/A
10. Amendment originates from: Sponsor Principal Investigator Jenecia Fairfax
11. Please check all categories where changes are being made:

____ Advertisement
____ Consent Form/Information Sheet
____ Investigator's Brochure
____ Risks and/or benefits
X Other
X Protocol Changes (study design, enrollment criteria, treatments)
____ Administrative Changes (names, addresses, spelling, grammar, title etc.)

11. Provide a narrative summary of the proposed amendments to the protocol (excluding administrative changes) that describes the nature and rationale for the changes for each item checked in # 10. Use an additional sheet if necessary. Inclusion criteria to be changed: **residence in Detroit changed to residing in Southeastern Michigan and treated at WSU/DMC Stroke Program Clinic and/or the Rehabilitation Institute of Michigan Clinic.** This would provide more diversity in the sample while still maintaining the urban focus of the study. **Age over 55 to be changed to over 50.** The research has shown that younger stroke survivors reported more change in quality of life, therefore the wider age span would provide for better statistical variation. **Time since stroke to be changed to at least four months post stroke** because the literature shows that the majority of functional improvements occur around three months and many increased benefits are dependent on the type and quality of social supports between three to six months.

The request for participation letter is to be changed (see attachment) because I will not be provided access to the databases due to HIPA and will therefore need to have those persons interested in participating contact me.

New

Request for Participation

[redacted]
Detroit MI 48207

My name is Jenecia Fairfax. I am a nurse working on my doctorate at Wayne State University. I am doing research about stroke survivors. The purpose of this study is to learn about the factors that contribute to the quality of life after a stroke. You have been identified as a possible research participant.

If you would like to participate in this study please call Jenecia Fairfax at [redacted]. I will answer any questions you have and set up an appointment to meet with you at your convenience at home or at the clinic during your follow-up visit. It will take about one (1) hour, one time only, to complete the study questions.

Thank you.

Jenecia Fairfax, MSN, RN

APPROVED

JUL 3 1 2001

WAYNE STATE UNIVERSITY
MEDICAL INVESTIGATION COMMITTEE

WAYNE STATE UNIVERSITY

HUMAN INVESTIGATION COMMITTEE
4201 St Antoine Boulevard - UHC-6G,
Detroit Michigan 48201
Phone: (313) 577-1628
FAX: (313) 993-7122
HIC Website: www.hic.wayne.edu

Notice of Expedited Amendment Approval

To: Jenecia Fairfax
[redacted]
Detroit, MI 48207

From: Peter A. Lichtenberg, Ph.D. ________________
Chairman, Behavioral Institutional Review Board (B03)

Date: October 25, 2001

RE: **Expedited Amendment to Protocol #:** 06-68-01(B03)-ER "Theory of Qualiy of Life of Stroke Survivors" Source of Funding: King/Chavez/Parks Future Faculty Dissertation Award, BCBS of Michigan Student Award Program Grant

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The following requested change(s) to the above-referenced protocol have been **APPROVED** following **expedited review**, and are effective immediately.

- Receipt of a PI-initiated protocol change (inclusion criteria age range has been widened to include over age 40, previously stated as over age 50), submitted on behalf of the PI on **October 18, 2001**.

This protocol, as amended, will be subject to annual review by **July 2, 2002.**

APPENDIX C

Pilot Study

A pilot study was done to evaluate the reliability of the Stroke-Specific Quality of life (SS-QOL) instrument, to determine the time that it would take to complete the study instruments, and to identify any other problems related to administration procedures Twenty subjects (N=20) who met the inclusion criteria compromised the sample.

Completions of the measures took from 20 to 45 minutes. The investigator read the questions and recorded the participants answers except for the Visual Analog Scale. The demographic questionnaire was always completed first, followed by the Cognitive Scale of the FIM (a score of 5> was a criterion for inclusion). The VAS, SSQS and the SS-QOL were administered as follows 1) VAS, SSQS, SS-QOL, 2) SSQS, VAS, SS-QOL; or 3) SS-QOL, SSQS, VAS, in an attempt to avoid bias that might be introduced by the measures.

The participants ranged in age from 51 to 79 years with a mean of 62.65 (SD =7.7), ten were females, 17 African American, time since stroke ranged from 4 to 70 months, and number of strokes ranged from one to four. The demographic statistics are in Table 1.

The reliability alpha coefficient for the total scale was .92. The reliability for the subscales were vision .88, self-care .72, language .85, mobility .85, work/productivity .41, upper extremity .65, personality .76, mood .60, family roles .68, social roles .77, energy .79, and thinking .54.

The participant did not report any problems in answering the questions in the measures. They found the VAS easy to use. There were a few participants who became tearful when answering some of the questions on the SS-QOL; however, no one asked that the interview be stopped. The overall time for administering the measures was on average 35.5 minutes. The reliability of the SS-QOL was similar to the reliability reported by the authors.

Table 1
Demographic Characteristics of Pilot Study Participants (20)

Characteristic	Percentage
Gender	
Male	50%
Female	50%
Ethnicity	
African American	85%
Caucasian	10%
Multi-Racial	1%
Marital Status	
Married	15%
Single	25%
Separated	15%
Divorced	20%
Widowed	20%
Significant Other	5%
Religion	
Catholic	10%
Protestant	80%
Other	10%
Participation in Religious Activities	
Weekly	35%
Monthly	10%
1-2 a Year	40%
Inactive	15%

(table continues)

Table 1 (continued)
Demographic Characteristics of Pilot Study Participants (20)

Characteristic	Percentage
Living Condition	
Alone	30%
Spouse/Significant other	15%
Daughter/son	15%
Relative	25%
Friend	10%
Nursing Home	1%
Employment Status	
Working Full-time	10%
Working Part-time	10%
Retired	30%
Disabled	50%
Educational Level	
Grades 1-8	20%
Grades 9-12	65%
Grades 13-16	10%
Grades 17-22	5%
Number of strokes	
One	75%
Two	20%
Three	0%
Four	5%

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ABSTRACT

THEORY OF QUALITY OF LIFE OF STROKE SURVIVORS (TQLOSS)

by

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Advisor: Dr. Stephen Cavanagh

Major: Nursing

Degree: Doctor of Philosophy

This study tested a theoretical model of quality of life of stroke survivors derived from King's conceptual framework for nursing. The model proposed that stroke survivors' perceptual integrity (cognition), social support, and perception of level of disability would predict their quality of life. In addition, the relative contribution of age, time since stroke, and number of strokes to the stroke survivors quality of life was investigated.

Participants were 102 adult stroke survivors who attended one of two clinics affiliated with an urban university, ages ranging from 43 to 93 years the mean was 63.21 (S D = 10.54). Study measures used included the Cognitive subscales of the Functional Independence Measures, the Social Support Questionnaire Short Form, a Visual Analog Scale, and the Stroke-Specific Quality of Life Scale. A pilot study was conducted with 20 participants to validate procedure and measures. Structural equation model (SEM) analysis was used to examine the proposed model and to test the proposed hypotheses. The overall model fit was assessed and re-specification of the model was statistically judged and tested again to allow fro a meaningful interpretation.

Results revealed that perception of level of disability was a significant predictor of quality of life and explained 27% of the variance. Cognition had a negative and significant effect on perception of level of disability. Cognition also had a significant indirect effect on quality of life through perception of level of disability. However,

cognition showed a positive but nonsignificant relationship with social support, a positive but nonsignificant relationship with quality of life, and a nonsignificant indirect relationship with quality of life through social support. Perception of level of disability showed a negative and significant on quality of life. Social support showed a positive nonsignificant effect on quality of life and perception of level of disability. Age and time since stroke were not significantly related to quality of life. Number of strokes had an indirect and significant effect through perception of level of disability on quality of life. These findings have implications for nursing practice in the assessment and planning of interventions to improve the quality of life of stroke survivors. The findings provide empirical support for the middle range theory of quality of life of stroke survivors and lend credibility to King's conceptual framework.

AUTOBIOGRAPHICAL STATEMENT

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Educational Background

Wayne State University, Detroit, MI	PhD	2002
Wayne State University, Detroit, MI	MSN	1998
Hunter College, CUNY, New York, NY	BSN	1975
St. Luke's Hospital SON, New York, NY	Diploma	1961

Awards & Honors

2001-2002	WSU, College of Nursing Alumnae Association Doctoral Scholarship
2001	Blue Cross Blue Shield Foundation Student Award
2000	WSU King/Chavez/Parks Future Faculty Fellowship Dissertation Award
1999	Del Harder Research Day Best Novice/Student Presentation Rehabilitation Institute of Michigan
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1996-1997	WSU, College of Nursing Kenney Michigan Rehabilitation Award
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Memberships

Association of Rehabilitation Nurses
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Sigma Theta Tau international Nursing Honor Society – Lambda Chapter

Publications

Cavanagh, S. J., Hogan, K., Fairfax, J., Gordon, V., & Kopacz, M. (2002). Assessing cognitive function after stroke using the FIM instrument. *The Journal of Neuroscience Nursing, 34* (2), 99-104.

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Presentations

Paper Presentation: *Conceptualization of health-related quality of life of stroke survivors derived from King's Interacting Systems Framework for Nurses.* KING Conference, Tampa, January.

Paper Presentation: *Social supports of inner city stroke survivors,* Del Harder Rehabilitation Research Day, Rehabilitation Institute of Michigan, November.