INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps. Each original is also photographed in one exposure and is included in reduced form at the back of the book.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

UMI

A Bell & Howell Information Company
300 North Zeeb Road, Ann Arbor MI 48106-1346 USA
313/761-4700 800/521-0600

University of Alberta

Quality of Life of Stroke Survivors 1-3 Years Post-discharge

by

Peter J. Kim ©

A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements for the degree of
Master of Science

Department of Occupational Therapy
Edmonton, Alberta
Fall, 1997

0-612-22612-3

University of Alberta

Library Release Form

Name of Author: Peter J. Kim

Title of Thesis: Quality of Life of Stroke survivors 1-3 Years Post-discharge

Degree: Master of Science

Year this Degree Granted: 1997

Permission is here by granted to the University of Alberta Library to reproduce single copies of this thesis for private, scholarly, or scientific research purposes only.

The author reserves all other publication and other rights in association with the copyright in the thesis, and except as hereinbefore provided, neither the thesis nor any substantial proportion thereof may be printed or otherwise reproduced in any material form whatever without the author's prior written permission.

1712-11135 83 Ave
Edmonton, Alberta
T6G2C6

Date July 30/77

University of Alberta

Faculty of Graduate Studies and Research

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research, for acceptance, a thesis entitled, "Quality of Life of Stroke Survivors 1-3 Years Post-discharge" submitted by Peter J. Kim in partial fulfillment of the requirements for the degree of Master of Science.

Helen Madill, Supervisor

Sharon Warren

Sharon Warren, Co-supervisor

JVargo

Jim Vargo

DSaunders

Duncan Saunders

Masako Miyazaki

Date: July 29/97

DEDICATION

With love and joy I dedicate this work
to my wife, my son, and my parents
who are the foundation
of my contentment in life.

ABSTRACT

Adaptation to stroke requires complex, long-term adjustments to stroke survivors' lives. This study aimed at identifying those factors that influence quality of life (QOL) of 50 geriatric stroke survivors 1-3 years post-discharge. The objectives of this study were: 1) to describe the overall QOL of these stroke survivors, 2) to examine the relationships between sociodemographic variables, neurological variables, functional status, perceived health status, social support, depression, and overall QOL, and 3) to determine the best predictors of QOL. Most of the data was collected cross-sectionally using standardized questionnaires.

The overall QOL of the study participants was low despite a reported high ADL-capacity. The most significant contributors of QOL were depression, marital status, social support, and functional status: depression was the strongest predictor of QOL. Further, psychosocial factors affected QOL more than functional status. This study employed a multidimensional perspective and confirmed that adaptation to stroke involves much more than physical function. Thus, the rehabilitation program can be more effective if it takes a holistic approach to the patient's overall QOL.

ACKNOWLEDGMENTS

I want to thank Dr. Helen Madill and Dr. Sharon Warren, my co-superviors, for their guidance and constant support. I also want to thank Dr. Jim Vargo, Dr. Duncan Saunders, and Ms. Masako Miyazaki for their insightful contributions to this study.

A special thanks to Ms. Sandy Bird for her assistance in the sampling of study participants, and to Ms. Laura May for her data entry assistance.

I am thankful to the Glenrose Rehabilitation Hospital Research Department for providing funding to engage in this study and to Dr. Kerrie Pain and Ms. Margaret Hadley for aiding me in my application for the GRH research grant and to Ms. Hadley, once again, for recruiting a qualified research assistant.

I am deeply grateful to all the stroke survivors who participated in this study, for without their contributions, the completion of this project could not have been possible.

Throughout all my endeavors, God has been my source of strength and wisdom. I thank you, God.

TABLE OF CONTENTS

CHAPTER I. PURPOSE

CHAPTER II. RELATED LITERATURE REVIEW

CHAPTER III. METHODS

TABLE OF CONTENTS (continued)

CHAPTER IV. RESULTS

CHAPTER V. DISCUSSION

TABLE OF CONTENTS (continued)

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

CES-D	Center For Epidemiologic Studies-Depression
FAI	Frenchay Activities Index
FIM	Functional Independence Measure
MMSE	Mini-Mental State Examination
PHS	Perceived Health Status
QLI	Quality of Life Index
SSIPAD	Social Support Inventory for People with Acquired Disability:
TOTQUAL *(SSIPAD)*	Total Qualitative Score
TOTQUAN *(SSIPAD)*	Total Quantitative Score
PQUAL *(SSIPAD)*	Subtotal Qualitative Score of Personal Category
CQUAL *(SSIPAD)*	Subtotal Qualitative Score of Community Individual Category

CHAPTER I. PURPOSE

Problem Statement

Cerebrovascular accident (CVA), or stroke, is a major cause of disability among many elderly Canadians, and therefore presents a major social challenge (Petrasovits & Nair, 1994). In the last four decades, advances in medicine and technology, improved quality of care, and increased emphasis on health promotion have contributed to a reduction in the incidence of stroke (Duncan, 1994). However, despite this decline, improved survival rates and an aging population contribute to a growing number of elderly stroke survivors living in the community (Duncan, 1994).

The impact of stroke on an individual is usually unanticipated, and its effects are devastating (Farzan, 1991). Depending on the severity and mechanism of the stroke, it can leave a person with residual impairments of physical, psychological and social functions. The severity of disability varies greatly as this depends upon the level of mobility limitations, communication difficulties, or the behavioral and personality changes associated with any cognitive deficit. Therefore, the occurrence of a stroke often has a negative impact on the stroke survivor; increased dependency on others for activities of daily life, alteration in mood, and disruption in social interaction with family members have been reported (Biegel, Sales, Schulz, Rau, 1991). Such changes have a far-reaching impact on the person's quality of life.

Even though previous studies have shown that rehabilitation can help a stroke survivor to regain and maintain physical function (Niemi, Laaksonen, Kotila, & Waltimo, 1988; Nydevik & Hulter-Åsberg, 1992), therapeutic interventions that focus on physical restoration in isolation from the context of a person's psychosocial environments are insufficient to improve quality of life following disability (Law, 1991; Renwick, Brown, & Nagler, 1996). This narrow approach toward stroke rehabilitation usually identifies disability as a characteristic which resides in the individual rather than in the environment (Jongbloed & Crichton, 1990). Consequently, even though the field of rehabilitation has recently placed a growing emphasis on improving quality of life, functional status or health status are the usual criteria to measure quality of life (Renwick et al., 1996). This methodology tends to neglect the psychosocio-environmental influences which affect how individuals cope with stroke-related disabilities. Studies have shown that a significant number of stroke survivors with little or no physical problems still experience a deterioration in their quality of life over an extended period of time (Ahlsiö, Britton, Murray, & Theorell, 1984; Niemi et al., 1988; Nydevik & Hulter-Åsberg, 1992). Improved functional status may be of little consequence if individuals are unable to resume meaningful and productive social roles within their environment. If current approaches to rehabilitation do not lead to an improvement in the client's perceived quality of life, these should be reevaluated, and further research should be conducted to determine what other factors need to be considered. The general purpose of this study was to identify those factors which predict satisfactory quality of life for stroke survivors.

Objectives of the Study

The primary objectives of this study were 1) to describe the overall quality of life of community-based stroke survivors 1 to 3 years after discharge from a local rehabilitation hospital, 2) to examine the relationship between QOL and possible predictors including functional status in terms of basic activities of daily living (BADL) and instrumental activities of daily living (IADL), perceived social support, perceived health status, and post-stroke depression, 3) to examine the influence of eight possible intervening socio-demographic and stroke-related variables on QOL: age, gender, marital status, education, income, living arrangement, stroke type, and localization of lesions, and 4) to perform a multivariate analysis to determine which combination of all the variables measured best predicts QOL for long-term survivors of stroke.

CHAPTER II. RELATED LITERATURE REVIEW

Profile of Stroke

Duncan and Badke (1987) defined cerebrovascular accident as:

> the abrupt development of focal neurological signs and symptoms caused by a pathologic process in a cerebral blood vessel, which results in the destruction of neural tissue—strokes may be divided into ischemic or hemorrhagic phenomena, although these events coexist. Ischemic strokes follow the sudden interruption or insufficiency of blood supply to the brain, with resultant infarction. In strokes caused by hemorrhage, on the other hand, while there is a degree of associated, tissue destruction, the rapid intracerebral accumulation of blood under arterial pressure may act as an expanding mass lesion, displacing or compressing adjacent brain tissue (p. 49)

Stroke is one of the most common causes of disability among elderly Canadians (Petrasovits & Nair, 1994). According to the recent survey by the Heart and Stroke Foundation of Canada (1996), every year, approximately, 40,000-50,000 Canadians suffer a stroke. About two-thirds of them are over the age 65 (Heart & Stroke Foundation, 1996). Currently there are 200-300,000 stroke survivors in Canada, and it is estimated that close to two-thirds of those who survive have some degree of permanent disability (Heart & Stroke Foundation, 1996). It follows that most stroke survivors have significant disabilities requiring a program of comprehensive, intensive rehabilitation in an inpatient setting. Based on the latest Canadian statistics, CVA accounts for over 67,000 hospital discharges and 3.2 million days of hospitalizations per year (Petrasovits & Nair, 1994). Cardiovascular disease, principally ischemic heart disease and stroke, is responsible for approximately $17 billion in direct and indirect health care costs annually (MacLean, 1994). With a growing aging population, the burden of stroke, as measured in terms of mortality rates, disability and long-term health care costs, remains a major challenge for health promotion and health care policy (Petrasovits & Nair, 1994).

When an individual suffers a stroke the event affects family unity, changing their pattern of life and challenging their ability to cope. The illness and residual problems of the stroke survivor impact other members of the family, and conversely, the reactions of the family members affect both the survivor and other family members (Short, 1981). Much of the literature on the impact of stroke on the family focuses on multiple stressors and negative outcomes (Evans, Bishop, & Ousley, 1992). These studies suggest that stroke can diminish the quality of life and the well-being of patient's families (Anderson, Linto, and Stewart-Wynne, 1994; Holbrook, 1982; Evans et al., 1992; Kinsella & Duffy, 1979). For example, Anderson et al. (1994) found a high level of emotional distress among family members of stroke survivors and suggest that many of them have unmet psychosocial needs because of their caregiving burden. The problems reported by families predominantly include physical exhaustion, psychological distresses, maladjusted marital relationships, and social isolation (Anderson, et al, 1994; Evans et al, 1992). Shortened hospital stays mean that stroke survivors will receive more of their care in the community, increasing the burden on families. Stroke affects long-term well-being of both the survivors and family members (Anderson, et al, 1994; Evans et al, 1992).

The impact of stroke on an individual is usually unanticipated and devastating (Farzan, 1991). Depending on the severity and type of the stroke, it can leave a person with residual impairments of physical, neurological functions such as incontinence, perceptual problems, sensory deficits, cognitive deficits, paralysis, and communication difficulties. In addition to an array of physical and neurological problems, persons with stroke frequently experience clinically significant depression and anxiety. Stroke can be a degrading experience when a person can no loner conduct their own personal care. Self-esteem problems are magnified if there are communication difficulties and alteration in physical appearance. Instead of feeling like a useful member of society stroke survivors may consider themselves a burden to family and friends. The predominant negative outcomes reported by stroke survivors include: decreased life satisfaction, physical problems, psychological distress, and decreased socialization. Thus, the occurrence of a stroke often results in negative life changes for the stroke survivor, and such changes have a far-reaching impact on the stroke survivor's quality of life. Studies indicate that the most severe disabilities, which result in institutionalization of stroke survivors, are the least prevalent. The more common types of disabilities are those in which psychosocial and environmental factors play a large part: these include decreased social life, altered family roles, psychological distress, and limited access to public buildings and transportation (Short, 1981). Therefore, the assumption that successful physical rehabilitation is equivalent to psychosocial rehabilitation, satisfactory adjustment to disability, and community reintegration is unfounded (Farzan, 1991). Therefore, stroke rehabilitation programs should use an holistic approach to promote more effective adjustment for stroke survivors and their families.

Aspects of Quality of Life after Stroke

The focus of rehabilitation is not simply to cure, but to improve quality of life for people with disability (Whiteneck, 1994; Wood-Dauphinee & Küchler, 1992). Few Canadian studies have examined quality of life, and the bulk of those dealing with stroke survivors are foreign (Ahlsiö et al., 1984; de Haan, Limburg, Van der Meulen, Jacobs, and Aaronson, 1995; King, 1995; Niemi et al., 1988; Nydevik & Hulter-Åsberg, 1992).

Studies using both quantitative and qualitative approaches reported that a large proportion of stroke survivors followed for as long as 4 years had a decrease in quality of life (Ahlsiö et al., 1984; Becker, 1993; Kelly-Hayes & Paige, 1995; Niemi et al., 1988; Nydevik & Hulter-Åsberg, 1992). As stroke-related disability is a multidimensional phenomenon, stroke survivors' perceived quality of life should also be viewed as multidimensional. The next section explores the nature of quality of life: its conceptual framework, underlying assumptions, and the factors likely to influence quality of life after stroke.

Conceptual Framework

Using quality of life as an outcome criterion has been a controversial issue in the field of health care (Grant, Padilla, Ferrell, & Rhiner, 1990). Since quality of life is a multidimensional concept, existing definitions lack clarity (Fallowfield, 1990; Ferrans, 1990b; Goodinson & Singleton, 1989). Lack of consensus regarding a satisfactory definition of quality of life has complicated the operationalization of this concept as an outcome criterion. Quality of life can be defined by a broad range of life domains which include psychosocial, physical, and social well-being (Calman, 1989; Grant et al, 1990). The most commonly used dimensions are physical function and psychosocial well-being which includes "life satisfaction" (Ferrans, 1990b; Grant et al. 1990; Padilla, Present, Grant, Metter, Lipsett, & Heide, 1983). Many authors believe that individual perception is integral to the concept of quality of life (Calman, 1989; Ferrans, 1990b; Oleson, 1990). The underlying assumption is that as people's values differ, so does the impact of functional limitations on various aspects of their lives (Ferrans, 1990b). Assumptions such as this one focus on the subjective experiences of individuals rather than on the objective conditions (e.g., income) of their lives. With a growing emphasis on health promotion and empowerment of individuals, a conceptual framework, which emphasizes the patient's own perception of quality of life, is gaining wider acceptance among the health-related professions (Schipper, Clinch, & Powell, 1990). Therefore, for the purposes of this study quality of life was defined as a subjective "experience manifested by satisfaction with life domains of importance to the individual" (Oleson, 1990, p.188).

Health in a Socio-ecological Perspective

Definitions of health have shifted from the absence of illness in the medical model, through the influence of World Health Organization's (WHO) definition of health as a state of complete physical, mental, and social well-being, to greater emphasis on the concept of multiple determinants of health (Letts, Fraser, Finlayson & Walls, 1993; Pollock, 1992; Rootman & Raeburn, 1994). Health is defined within a broader context of health determinants such as personal behaviors, lifestyles, the organization of health care, and physical and social environments in which people live (Lalonde, 1975; Siler-Wells, 1988). This broader view of health implies that it has other domains besides physical capacity (Renwick et al., 1996).

The socio-ecological concept of health relates primarily to the individuals' ability to achieve their potential and to respond positively to the challenges of their environment (Epp, 1986). This perspective presents good health as a basic life necessity for everyone; health is what one must have to accomplish other things in life. Health is therefore seen as a resource for everyday life, an essential dimension of one's quality of life (World Health Organization, Health and Welfare Canada & Canadian Public Health Association, 1986). "Quality of life in this context implies the opportunity to make choices and to gain satisfaction from living"(Renwick et al., 1996, p.30). The notion of health has thus moved towards a socio-ecological understanding of the interaction between individuals and their social and physical environment. The link between people and their environment constitutes the basis for a socio-ecological concept of health (WHO et al, 1986) which is central to health promotion. Health promotion's broader perspective acknowledges the significant influence of environmental factors on people's health and quality of life (Renwick et al., 1996). The concept of healthy environments and the creation of conditions or surroundings conducive to health, are therefore critical in fostering quality within the lives of people with or without disability.

Stroke in a Socio-ecological Perspective

Stroke presents a complex and significant public health challenge with broad individual, family, and societal implications. Stroke-related disability is a multidimensional phenomenon. The current clinical or individual approach toward stroke rehabilitation usually identifies disability as a characteristic which resides in the individual rather than in the environment (Jongbloed & Crichton, 1990). The field of rehabilitation typically measures successful outcomes in terms of the level of physical independence achieved in activities of daily living. Thus, it tends to neglect the socio-environmental influences which affect how individuals cope with stroke-related disabilities. The literature on stroke recovery clearly indicates that physical parameters focusing on stroke severity or ADL-capacity alone do not fully explain variations in perceptions of quality of life or in the level of community reintegration. Labi, Phillips, and Gresham (1980) found that a sizable proportion of stroke survivors reported significant levels of disability despite complete physical restoration. Therefore, successful adjustment to the environment is critical in mediating the effects of impairment and disability on the degree of community reintegration and quality of life.

There is a growing recognition that the problems of seniors with disabilities largely depend on social and environmental circumstances (Jongbloed & Crichton, 1990). This indicates the need to expand the definition of health to include environmental variables. The new socio-ecological definition of health regards disability as a product of the interaction between the individual and the environment. From this perspective, the challenges related to disability are not solely the consequence of personal and physical limitations. Whether or not disability leads to a handicap depends upon social and environmental circumstances and various factors which can modify the results of disablement. Because stroke-related disability is a multidimensional phenomenon, the quality of life for stroke survivors should also be viewed as multidimensional. Thus, the quality of life of stroke survivors in the community is related to factors such as physical impairment or disability, perceived social environment which includes family support and community or home-based support, societal limitations attributable to social policy and structural or attitudinal barriers imposed by society (Whiteneck, 1994). In this context, adjustment implies coming to satisfactory terms with the environment and oneself, and it involves both a personal and social point of view. A growing number of studies suggest that during times of stress, the individual needs to perceive that others are available to help cope with demands posed by the environment

(Chappell, 1992). Whiteneck (1994) argues that societal limitations such as architectural barriers and prejudice may be more handicapping than the severity of physical impairment or disability itself. He further states that many personal resources such as a high level of education, productive work history, adequate financial resources, and personal motivation, all seemingly unrelated to impairment or disability, may be critical in mediating the impact of impairment or disability on social role fulfillment (Whiteneck, 1994). Consequently, the success of community reintegration is mainly dependent on social and environmental circumstances and not solely on level of independence or function.

Occupational Therapy Perspective on Health

The notion of health has shifted towards a socio-ecological view of interaction between individuals and their social and physical environment. This concept of health and health promotion is congruent with the client-centered practice of occupational therapy. Occupational therapists have thus been challenged to integrate environmental concerns into clinical practice (Law, 1991; Letts et al., 1993). In response to changes in the health paradigm, the occupational therapy profession is in the process of clarifying and redefining its body of knowledge. Occupational therapy's unique understanding of the complex, dynamic relationship between occupation and health is expanding (Canadian Association of Occupational Therapists & Department of National Health and Welfare, 1991). Occupational therapists have long believed that individuals have the right to autonomy and self-determination, that individuals have the ability and capacity for change, and that individuals shape and are shaped by their environment (CAOT & DNHW, 1991; Polatajko, 1992). Occupational therapists have always recognized the importance of the effects of the environment on individuals and communities. The literature suggests that the client-centered model of occupational therapy practice is consistent with the current socio-ecological views. Despite this congruence, occupational therapists traditionally believe that clients can control environmental influences through their actions, and thus they tend to focus on adapting the client to the immediate environment (CAOT & DNHW, 1991; Law, 1991; Madill, Townsend, & Schulz, 1989). If, instead, clients' occupational function is considered in the current socio-ecological understanding of interaction between clients and their daily environment, barriers to occupational function would be the result of inadequate social and environmental circumstances (Law, 1991). Maximizing occupational function could therefore be achieved by changing the environment, rather than changing clients (Law, 1991). Consequently, occupational therapy's leadership is refocusing on the interaction between individual and environmental variables and viewing disability as a collective problem, caused by inadequate personal and environmental conditions (CAOT & DNHW, 1991; Letts et al., 1993; Letts, Law, Rigby, Cooper, Stewart, & Strong, 1994).

With a growing emphasis on "the interconnections between a person's performance and environment, occupational therapists are redefining the concept of optimal occupational performance" (CAOT & DNHW, 1991, p.vii). That is, occupational therapists have become increasingly aware of the need to collaborate with their clients to set and define the clients' own health agendas, and facilitate their optimal occupational performance. Further, occupational therapists are acknowledging the value of not only independence but also interdependence between people (CAOT & DNHW, 1991). This socio-ecological view of health has challenged occupational therapists to see disability in environmental terms. If environments continue to promote dependency and do not effectively resolve the problems of disability, then intervention must be aimed at the modification of the environment (CAOT & DNHW, 1991; Law, 1991). Improved physical function may be of little consequence if individuals are unable to resume meaningful and productive social roles within their environment. Thus, an improved balance in the focus of rehabilitation is required, and environmental intervention has the potential to make a significant impact to the occupational function of stroke patients (Law, 1991). The purpose of this study was to determine those biopsycosocio-environmental factors which predict satisfactory quality of life in persons after stroke.

Functional Status and Its Impact on Quality of Life

Functional status, referred to as the degree of independence in performing activities of daily living (ADL), is of particular significance. ADL is the most commonly used measure of quality of life in the literature on the impact of stroke. Studies of patients with strokes have generally focused on the physical aspects of stroke recovery, and have shown that a majority of patients report depression and deterioration in quality of life despite their level of physical recovery (Ahlsiö et al., 1984; Fiebel & Springer, 1982; Labi et al., 1980; Niemi et al., 1988; Nydevik & Hulter-Åsberg, 1992; Viitanen, Fugl-Meyer, Bernspäng & Fugl-Meyer, 1988). For instance, in a longitudinal study of the quality of life of patients following stroke, Ahlsiö et al. (1984) used a visual analogue scale to investigate change in quality of life and found that even though lower quality of life was associated with greater disability, perceived quality of life failed to improve over time even when ADL function increased. To validate this discovery, Niemi et al. (1988) used a questionnaire concerning four domains of life (work conditions, activities at home, family relationships, and leisure time activities) to assess the quality of life for 46 stroke survivors under the age of 65 years for 4 years after their first stroke. Niemi and his associates (1988) reported deterioration in the quality of life of most participants (83%) despite adequate functional recovery four years after onset of stroke. These findings have been further validated by Nydevik and Hulter-Åsberg (1992) who found that despite stable ADL-function, stroke patients had a significantly high degree of subjective sickness impact three years after onset of stroke. The impaired functional status has a clear-cut impact on deterioration of quality of life; however, the patients' perception of their own health status, not ADL-capacity, contributes significantly to the variation in quality of life. In a quantitative study of life-satisfaction of long-term stroke survivors, Viitanen et al.(1988) found those with hemiplegia in particular, but also many unimpaired and nondisabled stroke survivors, were permanently handicapped after stroke. Independence in functional status, thus, does not mean absence of handicap[1] which is closely related to quality of patient's life in the community (Wood-Dauphinee & Küchler, 1992).

Social Support and Health

The contemporary view of social support has a broad context; social support is recognized to be complex and multidimensional. "Social support reflects a type of resource for meeting personal needs, and in times of crisis, during major transitions, and in response to unexpected changes, the role of this resource thus is critical" (Evans & Northwood, 1983, p. 61). Social support has emotional, instrumental, informational, and affirmational

---

[1] Handicap is defined as " a disadvantage for a given individual that limits or prevents the fulfillment of a role that is normal (depending upon age, sex, social and cultural factors) for that individual" (World Health Organization, 1980, p.183)

functions (Chappell, 1992; Cohen & Syme, 1985). There is a rapidly expanding body of literature on the effects of social support on mental and physical health (Chappell, 1992; Cohen & Syme, 1985).

Social support research has viewed social support within a stress-illness framework. Researchers have suggested specific ways in which social support may influence health and functioning. Stewart (1995), in her review of social support research, points out three ways in which investigators have hypothesized how health outcomes may be affected by social support: a) social support may prevent or influence stressful events (mediating effect); b)social support buffers or cushions stressful events (buffering effect); and c) social support may have a direct effect on health (main effect). Stewart (1995) indicates that it is important to learn more about the mechanisms which makes social support effective. In the studies of burden caused by illness, researchers argue that whereas an increase in the level of life stress can negatively affect health outcomes, the impact of this increase is offset or buffered by adequate social support (Cohen & Willis, 1985; Eckenrode & Gore, 1990; Williams, 1993).

In this stress-moderating model, conditions of high stress can be improved greatly by social support. Social support can ease the coping process, or help people to overcome or adapt to a stressor. It intervenes between the stress experience and illness, reducing the stress, allowing illness behavior to change, or facilitating psychological growth and healing (Cohen & Willis, 1985). When the experiences of caregivers are viewed within the larger framework of stress, studies indicate that caregiving activities may negatively affect the long-term well-being of family members (Anderson, et al., 1994). Caregiving, then, may lead to stress effects in the caregiver such as physical exhaustion, psychological distresses, decreased quality of life, and social isolation (Anderson et al., 1994; Biegel et al., 1991; Evans et al., 1992). The support of caregivers' social networks or community-based support systems may moderate the impacts of these stressors by supplying the resources caregivers desperately need to fulfill the demands posed by their caregiving responsibilities (Chappell, 1992). Similarly, the impact of stroke on an individual is usually unanticipated, and its effects are devastating (Farzan, 1991). Depending on the severity and type of the stroke, it can leave a person with residual impairments of neurological, physical, and psychological functions. These problems have a far-reaching impact on the person's ability to perform daily activities, to get around, and to fulfill social roles, whether at home or in the community (Nydevik & Hulter-Åsberg, 1992; Niemi et al., 1988). Self-esteem problems are magnified if there are communication difficulties and alteration in physical appearance (Marshak & Seligman, 1993). Instead of feeling like a useful member of society the person may consider himself a burden on family and friends (Marshak & Seligman, 1993). Studies have shown that informal social support can greatly improve functional state of the stroke survivors since social support may serve to moderate the consequences of chronic illness (Cohen & Willis, 1985; Evans & Northwood, 1983). Further, when stroke survivors experience feelings of low self-esteem, of personal limitations and a loss of control in their lives, a social support program can provide opportunities for stroke survivors to accept and cope with these feelings of loss, and can encourage them to rebuild their self-esteem (King, 1990).

Differential Effects of Social Support on Quality of Life

Recently the notion of health has moved towards a socio-ecological understanding of the interaction between individuals and their social and physical environment. Whether or not impairment and disability lead to a handicap may depend upon social and environmental circumstances and not solely on the level of physical independence or function. Therefore, a successful adaptation to the environment is critical in mediating the impact of impairment and disability on quality of life.

In addition to the relationship of functional status to quality of life, of interest in this study are the effects of the social environment, specifically informal and formal social support, on the quality of life of stroke survivors in the community. The individual who returns to the community after a stroke encounters problems beyond their level of independence in activities of daily living. These individuals and their families are in need of support in the struggle to improve the quality of their lives. Formal or informal social supports are known to delay or reduce the risk of institutionalization, and generally improve well-being and the degree of life satisfaction of elderly in the community (Sauer & Coward, 1985). There is a rapidly expanding body of literature on the effects of social support on mental and physical health (Chappell, 1992; Cohen & Syme, 1985). A few empirical studies have shown potential effects of social support resources relevant to this study.

When specific studies of social support are compared, study findings are not always consistent. In a review of studies on the impact of stroke on the patient and family, Biegel et al. (1991) report that psychological and social factors, including perception of the stroke event and the presence of social support, may be as important as physical function in determining the patient's quality of life and return to pre-stroke levels of social role fulfillment. Further, in a cross-sectional study examining the relationship of social support to quality of life of individuals 1 to 3 years after onset of stroke, King (1995) found that perceived social support, depression, and functional status contributed to 38% variance in quality of life. Similarly, in studies investigating adaptation to disease, Antonucci (1990) finds that the perception of adequate support is strongly associated with psychological and social functioning and quality of life. On the contrary, Lin, Simeone, Ensel, and Kuo (1979) reported a very weak association between social support and quality of life. Although social support can have positive as well as negative effects, in general, a growing number of studies indicate that during times of stress, the patient needs to perceive that others are supportive or will be there if necessary to help cope with demands posed by the environment (Chappell, 1992). Considering the stressful nature of adapting to the residual impairments and disabilities of stroke, one would expect that a person's quality of life would be related to perceived social support, as social support is known to mediate the effect of stressful experiences on quality of life (Cohen & Syme, 1985). This study evaluated the impact of both quantitative and qualitative aspects of support on quality of life .

Types of social support

A modest body of research has shown that social support, whether it is emotional, instrumental, or informational, has beneficial effects on stroke patients (Evans & Northwood, 1983; King, 1995; Kinsella & Duffy, 1979; Friedland & McColl, 1987; Mahoney, 1986; Stephens, Kinney, Norris, & Ritchie, 1987). Most studies have examined the effects of social support resources during recovery. However, few of these studies have used widely-accepted measures of social support, and fewer still have employed longitudinal methods.

Social support is found to be most effective when it is perceived by the patients to meet their emotional needs (Evans & Northwood, 1983). Robertson and Suinn (1968) demonstrated a relationship between greater family support and understanding with the rate of progress in stroke rehabilitation. Other authors have found a significant relationship between recovery and instrumental support (Brocklehurst, Morris, Andrews, Richards, & Laycock, 1981; McLeroy, DeVellis, Devellis, Kaplan, & Toole, 1984). For instance, McLeroy et al. (1984) found a significant relationship between instrumental support and functional status at 6 months but did not examine variations in quantity of support. Glass and Maddox (1992) found a strong relationship between functional independence and instrumental support when it was provided in moderate amounts. They further suggest that too much instrumental support may promote dependency and lack of motivation in achieving functional independence. Glass and Maddox. (1992) have found that the efficacy of informational support depends on illness severity. Patients who have suffered more severe strokes are less able to make use of informational support as a result of a greater level of cognitive impairment.

Sources of social support

Until recently, interest in social support for stroke rehabilitation was limited primarily to the role played by the family and to the inpatient period of rehabilitation (Friedland & McColl, 1987). Various individuals and institutions can be seen as providers of social support for stroke survivors. Social support can take different forms and fulfill different needs, and it can be found outside the family and beyond the active rehabilitation phase of treatment.

In an analysis of the sources of social support in stroke recovery, Friedland and McColl (1987) have found that the types of social support that are most influential are support from a close, personal source, support from individuals in the community (non-kin), and overall satisfaction with support. In addition, they have also shown that the impact of professional sources of support is minimal. On the contrary, Anderson (1993) assessed differences in perceived social support between students with disability and non-disabled students and emphasized the importance of professionals in overcoming the potential barriers to post-secondary education. These studies with different populations support the view that different sources of support may be more effective for different problems (Pearlin, 1985).

The process through which social support and quality of life are related has not been well developed in the literature. Nevertheless, the results obtained from the studies of social support endorse further inquiry into the relationship of social support to long-term quality of life. Because social support has been shown to act as a buffer against stress in a variety of situations (Cohen & Syme,1985; Friedland & McColl, 1987), research was conducted to confirm whether persons who report experiencing greater social support would also report greater life satisfaction.

Perceived Health Status

Perceived health status is defined within a broader context of health determinants such as social environments, personal behaviors, and lifestyles (Siler-Wells, 1988). Norland (1994) found that elderly Canadians rated their own health as good, very good, or excellent despite the increasing number of chronic conditions and disabilities, but positive responses declined with age. However, stroke survivors are apparently more likely to rate their health as poor than age-matched nondisabled seniors living in the community (Becker, 1993; Nydevik & Hulter Åsberg, 1992). Further, studies have found that both a patient's perceptions of specific impairments and general health status are appropriate outcome measures in clinical trials (Spilker, 1990; Whiteneck, 1994), and that perceived health status is closely related to quality of life (de Haan, Aaronson, Limburg, Hewer, & van Crevel, 1992).

Post-Stroke Depression and Quality of Life

Other intervening variables or factors affecting quality of life of the community-based stroke population have been identified. In addition to limited evidence about functional health (e.g. self-care) and social support, the effects of psychological (e.g. depression) and physical problems (e.g. motor deficits) on quality of life of persons with stroke have been identified. Previous studies found that depression affected 26% to 65% of stroke survivors (Fiebel & Springer, 1982; Kaun, 1990; King, 1995; Robinson & Price,1982; Sjogren,1982). On the contrary, House, Dennis, Mogridge, Warlow, Hawton, & Jones (1991) found that post-stroke depression affected less than 2%.

In addition, with regard to the relationship of post-stroke depression to quality of life, when specific studies are compared, study findings seem to be inconsistent. Using the prospective study, Niemi et al. (1988) found that the incidence of post-stroke depression was 48% and a tendency to depression was one of their strong predictors of the quality of life. Similarly, King (1990) reported that quality of life was negatively affected by depression, and it was the strongest predictor of overall quality of life of 86 post-discharge participants with stroke. Further, Ahlsiö et al. (1984) reported results emphasizing the importance of depression; they found that depression and anxiety affect quality of life as much as physical disability. Other investigators also observed problems of social functioning in depressed patients even two years after stroke (Parikh, Lipsey, Robinson, and Price, 1987). Still other authors did not find any association between social dysfunction and depression (Stern, & Bachman, 1991), while some found that patients with depression were more disabled in physical activities and language functioning than non-depressive patients but reported no correlation between depression and quality of life (Parikh, Robinson, & Lipsey, 1990).

Other Factors Influencing Quality of Life in Stroke

Other health and socio-demographic factors have been studied for their influence on quality of life. As for the type of stroke and the localization of lesions, in a four year follow-up study, Niemi et al. (1988) found that stroke patients with subarachnoid hemorrhage (SAH) had significantly milder deterioration in quality of life compared to patients with brain infarction. Further, patients with either right- or left-hemisphere lesions were reported to have more severely deteriorated quality of life compared to patients with no localizable or brain stem lesions. de Haan et al.(1995) found that survivors of hemorrhagic strokes did not evidence lower quality of life than survivors of ischemic strokes. The influence of age and gender factors have also been studied with varying success. Niemi et al.(1988) found that older (51-64 yr.) patients experienced more severe deterioration in quality of life than younger (17-50 yr.) patients, and men had a slightly more deteriorated quality of life. On the contrary, Ahlsiö et al.(1984) found no significant age and gender differences when ADL capacity was kept constant.

In general, good health, marital status, socioeconomic status, and better education were found to be positively associated with quality of life (Palmore & Kivett, 1977). However, Labi et al. (1980) found that individuals with higher education and income levels had a lower quality of life after stroke. The authors speculated that the deterioration in quality of life was related to decreased participation in socialization as result of a perceived stigmatization associated with disability.

Summary Statement

Cardiovascular accident (CVA) is a complex and significant public health challenge. Previous literature suggests that the specific nature of post-stroke disability is a combination of physical, psychological and social consequences and resources. These become the substrata for quality of life. However, in spite of extensive research on stroke, little attention has been focused on multi-dimensional aspects of quality of life in stroke outcome research. Rather, physical dysfunction has long been the primary focus in stroke research, and in rehabilitation, quality of life has been commonly assessed in terms of functional status (Renwick et al., 1996).

The presence of psychosocial dysfunction has always been acknowledged but has been emphasized less; its potential influence on quality of life has not yet been fully explored. Therefore, there is a need to study the multi-dimensional process of quality of life and to begin to accumulate evidence on the nature of the interaction of physical, psychological, and social factors in predicting quality of patients' lives after stroke. The roles of socio-demographic variables, stroke-related variables, functional status, perceived health status, post-stroke depression, and social support in quality of life after stroke are important areas which require further research. Thus, this study employed a multidimensional conceptualization of quality of life in the belief that stroke recovery is a complex phenomenon. Research of this type is critical in providing appropriate rehabilitation interventions and thereby improving the quality of community life for persons with CVA.

CHAPTER III. METHODS

Sampling of Study Participants

Participants were recruited through purposive sampling from a population of stroke survivors discharged from the Glenrose Rehabilitation Hospital (GRH) between 1993 and 1995 with a diagnosis of stroke. The advantage of using participants from one hospital was that criteria for diagnosis, functional status assessment, and discharge are standardized. A qualified research assistant (GRH nursing staff) screened charts to establish eligibility and recruited potential participants based on the inclusion and exclusion criteria. An introductory letter (Appendix A), briefly explaining the purpose of the study, was sent to all potential participants by the research assistant who then contacted them by telephone to inform them about the study and request their participation[2].

To be included in the study, participants must have sustained a stroke as an adult between the ages of 60 and 85 years. Similar age groups have been used in other stroke outcome studies (Ahlsiö et al, 1984; de Haan et al, 1995; Kaun, 1991; Nydevik & Hulter-Åsberg, 1992). Further, both ischemic and hemorrhagic strokes, because of their differential effects on stroke recovery, were considered in this research. Additionally, stroke survivors were not excluded based on the localization of brain lesions because the influence of this factor has been studied with varying success. Participants must also have suffered from a stroke for the first time, and must have been discharged at least 12 months but not more than 36 months previously from an in-patient rehabilitation facility. One- to three-year stroke survivors were

---

[2] Permission to release participants' names to the principal investigator was be obtained at this time.

recruited to strengthen the comparability of this study, as most stroke outcome studies have used similar participants (Ahlsiö et al., 1984; King, 1990; Nydevik & Åsberg, 1992; Vitanen et al., 1988). Further, studies have shown that the period of 3 to 12 months after stroke is critical in developing quality of life, and the degree of quality of life attained by one year after stroke generally persists (Sadin, Cifu, & Noll, 1994). Because the data collection process required a high level of cognition and communicability, stroke survivors with severe cognitive impairment and receptive or expressive aphasia were excluded from the study. Stroke survivors were also excluded on the basis of a history of psychiatric illness (e.g., schizophrenia) because of its possible confounding influence on quality of life. Likewise, stroke survivors with other degenerative neurologic diseases (e.g., multiple sclerosis) that could interfere with BADL or IADL function were not included in the study. For financial reasons, stroke survivors residing further than 80 Kilometers from Edmonton (round trip) were not included in the study.

A goal of 85[3] participants was set based on the sample size calculation shown in Appendix B to achieve .80 statistical power. Based on hospital admission data, approximately 250 patients per year are admitted with a diagnosis of CVA to the Glenrose Rehabilitation Hospital. Out of 433 geriatric stroke survivors (60 years or older) who were discharged between January, 1993 and December, 1995, 120 survivors met the inclusion and exclusion criteria. Out of these 120, initially 55 consented to participate in the study. Of these 55, 50 were able to fully participate in the data collection process. Because an unusually high number of participants refused to participate, the final sample size of 50

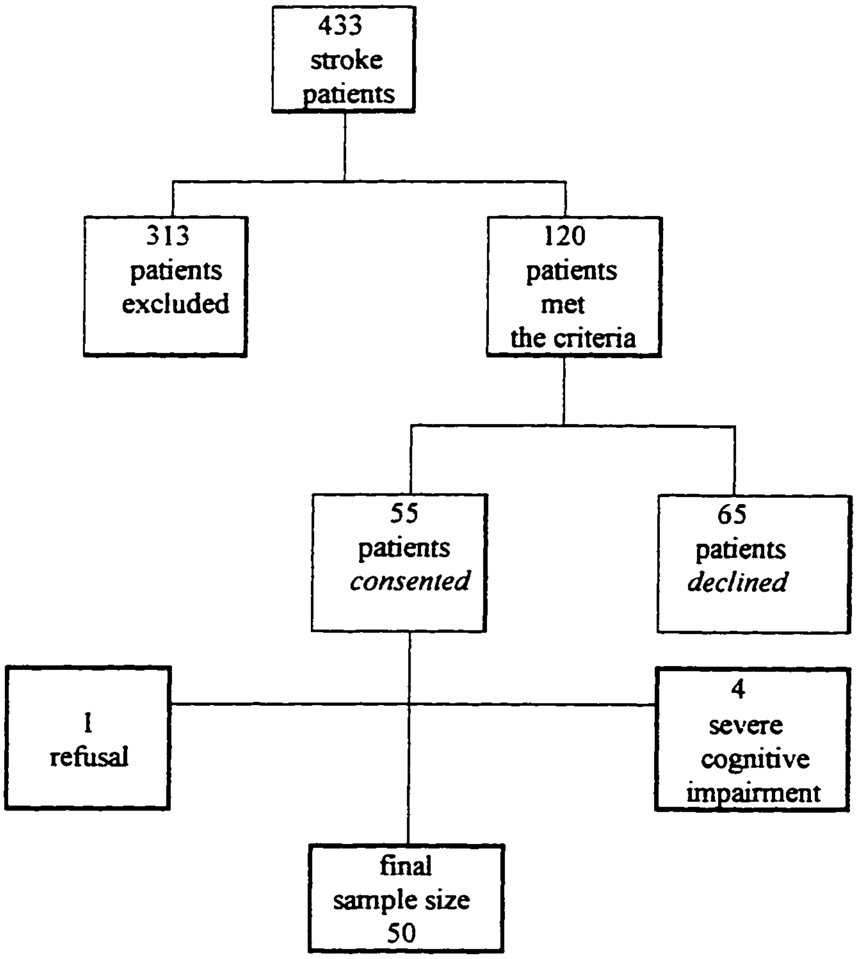
---

[3] The sample size of 85 was calculated based on the 5 independent dimensions of quality of life and 8 other intervening variables being measured

instead of 85 was obtained. No information was collected on why some individuals refused to participate so that it is impossible to determine whether the sample is biased in any particular way. It was not possible to compare respondents to nonrespondents on demographic data in their charts, since the GRH would not allow the principal investigator access to the charts of eligible patients who refused to participate. Therefore this approach could not be used to assess the representativeness of participants. The smaller sample size reduced the power of the study to .60. Figure I provides further information on how the present sample size of 50 was reached.

FIGURE I

Flow chart of sampling of study participants



Study Design

As many quality of life studies have employed a quantitative rather than a qualitative approach (Kelly-Hayes & Paige, 1995), a quantitative approach was also used in this study so that these results could be compared with others. In addition, a cross-sectional design was used to determine the relative impact of the degree of functional impairment, perceived health status, perceived social support, and post-stroke depression on quality of life of stroke survivors. The financial and time restraints prohibited any longitudinal design.

Procedures

Data Collection

This research utilized face to face data collection using a number of standardized instruments. Most of the data was collected cross-sectionally during participant interviews. However, supplementary data such as stroke survivors' neurological status was retrieved retrospectively from the hospital's medical record using the Neurological Status Form (Appendix C) and verified at the time of data collection. Prior to administering questionnaires, the principal investigator provided participants with all necessary information about the study. Then consenting participants were asked to sign the consent form (Appendix D), and a copy was left with them. All questionnaires were administered in the homes of participants. All data collection was carried out by the principal investigator and completed in a maximum of two home visits.

After ensuring that the consent form was complete, screening participants for sufficient cognitive abilities using the Mini-Mental State Examination (Appendix E), and obtaining relevant socio-demographic information using the Demographic Data Form (Appendix F), the principal investigator administered the remaining questionnaires. If the participant could not read and write proficiently, the investigator read the questions to the participant. Face to face data collection lasted approximately two hours; most stroke survivors were able to tolerate this length of interview and could maintain an appropriate level of concentration and interest.

Measurements

The questionnaire and measurement tools were pretested for clarity, length, participant's tolerance, and acceptability of procedures with three first time stroke survivors. A total of 7 measurement instruments used in the study are as follows: the Mini-Mental State Examination, Quality of Life Index (Appendix G), Functional Independence Measure (Appendix H), the Frenchay Activities Index (Appendix I), the Social Support Inventory for People with Acquired Disability (Appendix J), Perceived Health Status (Appendix K), and the Center for Epidemiologic Studies Depression Scale (Appendix L).

Screening

All eligible participants were screened for severe cognitive impairment using the Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975; Evelyn & Chui, 1987) at the initial interview. The maximum score for the MMSE is 30. Any individuals who scored less than 24 were excluded from the study because this score indicates cognitive deficits severe enough to interfere with their ability to provide accurate and valid information on questionnaires.

Quality of Life

Quality of life was measured using the Quality of Life Index (Ferrans & Powers, 1985). This index was originally developed to measure the quality of life of individuals with end stage renal disease. Thirty-four items included in the dialysis version were based on a literature review of issues related to quality of life and on reports from patients regarding the effects of hemodialysis. The original version was then modified to reflect the unique needs and concerns of stroke survivors (Ferrans & Powers, 1985; King, 1990). The revised QLI is a 72 item measure composed of two parts: the first part measures satisfaction with various domains of life, and the second part measures the importance of the same domains to the participants (Ferrans & Powers, 1985). The QLI covers four major underlying domains: health and functioning, socioeconomic, psychological and spiritual, and family. Participants are required to respond to the items on a six-point Likert scale in which the categories range from "very satisfied" to "very dissatisfied," and "very important" to "very unimportant" (Ferrans & Powers, 1992). The final quality of life score is obtained by weighting each satisfaction response with its paired importance response (Appendix M). The range possible for the overall score is 0 to 30, with higher scores indicating higher quality of life (Ferrans & Powers, 1985). The reliability of the QLI has been well documented. Test-retest correlations of .87 with a two-week interval and .81 with a month interval demonstrate the stability of this measure (Ferrans & Powers, 1985; King, 1990). Internal consistency of reliability of the QLI is supported by Cronbach's alpha coefficient of .91 for the entire instrument, .86 for the health and functioning subscale, .76 for the socioeconomic subscale, .84 for the psychological and spiritual subscale, and .32 for the family subscale (King, 1990). High internal consistency (except the family subscale coefficient) supports appropriateness of use of the QLI for this research.

Evidence of the criterion (concurrent) validity of the Quality of Life Index is mainly based on the correlations with the assessment of life satisfaction. An assessment of life satisfaction is considered appropriate as a criterion because the definition of quality of life guiding the QLI focused on the satisfaction with the areas of life that are important to the individual (Ferrans, 1990b). The correlation between the overall QLI score and the life satisfaction assessment for a large group of hemodialysis patients is .77 (Ferrans & Powers, 1992). However, Ferrans and Powers (1992) did not report criterion validity for use with stroke patients. Construct validity was also assessed using the known groups methods (Ferrans, 1990a) and the contrasted groups method (Ferrans & Powers, 1992). In the known groups method, a test was given to subjects with known characteristics, and the direction of differences in the scores was predicted (Ferrans, 1990a). Student T-tests were used to compare mean scores for each of the three grouping variables, and subjects who had less pain, less depression, and better coping mechanisms had significantly higher mean quality of life scores (Ferrans, 1990a). When the contrasted groups method was used to support the construct validity, it was found that on a social and economic subscale, those who had higher incomes had significantly higher quality of life scores than those who had lower incomes (Ferrans & Powers, 1992).

Possible Predictors of Quality of Life

Functional status

Functional status was measured using the Functional Independence Measure (FIM). The FIM is a measure of disability that has been developed for general rehabilitation patients, including those with stroke. The 18 items of the FIM is a comprehensive scale that includes BADL items, including a wide range of items concerning mobility, social behavior, communication, and cognitive impairment (Keith, Granger, Hamiliton, & Sherwin, 1987). Measurement of each item ranges from complete dependence (1) to complete independence (7) (Granger & Hamilton, 1993). The possible total scores range from a minimum of 18 to a maximum of 126 (Granger & Hamilton, 1993). High internal consistency of the FIM was supported by a Cronbach alpha of .92 reported for 86 stroke survivors (King, 1990). Further, convergence validity was supported by a sufficient correlation (Pearson correlation coefficient of .80) between the FIM and Frenchay Activities Index (FAI) for thirty-eight stroke survivors (Segal & Schall, 1994).

The FIM, although an adequate measure of BADL, does not assess the patient's ability to perform complex activities (IADL) such as housekeeping, recreation, hobbies, and social interaction. Because limitations in IADL may affect quality of life considerably, this variable was further measured using the Frenchay Activities Index (FAI) (Holbrook and Skilbeck, 1983). The Frenchay Activities Index was chosen because this instrument was developed specifically for use with stroke patients. The FAI measures lifestyle in terms of more complex physical activities and social functioning. It rates the frequency with which respondents perform 15 activities (e.g., gardening, washing dishes) that have been content-validated for application to the stroke population. The FAI is reported as adequate for internal consistency, Cronbach's alpha coefficients, .78-.87. (Schuling, de Haan, Limburg, & Groenier, 1993). Convergent validity is supported by a substantial correlation (Pearson correlation coefficient of .66) between the total scores of the FAI and the disability scores of the Barthel Index (Segal & Schall, 1994)

Perceived social support

Perceived social support was assessed using the Social Support Inventory for Stroke Survivors (SSIPAD). The SSIPAD, a self-report inventory in the form of a structured interview, was developed specifically for use with stroke patients (McColl & Friedland, 1989). The SSIPAD was constructed to measure the support perceived from five sources (personal ties, friends, community, group, and professional ties). Each of the five source sections includes 15 questions that correspond to dimensions of quality (reciprocity, dependability, closeness, & satisfaction) and quantity (frequency & intensity). Scores are calculated in each of the five source categories by summing quality and quantity questions within the category. The inventory also addresses concerns unique to the stroke population, such as change in available support since the stroke, and the need for both instrumental and emotional support. The advantages of the SSIPAD include high content validity and multidimensional scaling that is consistent with theoretical frameworks for social support. A recent review by McColl and Friedland (1989) reports that the SSIPAD has a test-retest reliability of .91 and internal consistency of .85 over one week.

Perceived health status

This variable was measured using a single age-referenced health question answered on a 5-point continuum, "excellent, good, fair, poor, bad". Self-reported health is deemed a strong and valid predictor of quality of life in the elderly population residing in the community (Mossey & Schapiro, 1982).

Post -stroke depression

This variable was measured using the Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff & Locke, 1985). The CES-D Scale is a self-rating scale designed for use in community surveys to measure the severity of depressive symptomatology. The CES-D Scale is a 20-item questionnaire investigating perceived mood and level of functioning within the past 7 days. Scores range from 0-60, with higher scores indicating increasing severity of depression. Scores of 16 or higher are considered indicative of depression. Shinar, Gross, Price, Banko, Bolduc, and Robinson (1985) have examined the inter-observer reliability and validity of the CES-D Scale as a measure of depressive symptomatology in stroke patients, and have reported that the CES-D Scale has an inter-rater reliability of .76, $p < .001$. Further, the CES-D scale scores are significantly correlated with the other depression measures such as Hamilton Depression Scale, Zung Depression Scale, and Present State Examination ($r=.57$, $r=.65$, and $r=.72$ respectively, $p<.002$). Thus, the CES-D Scale was found to be reliable and valid as a screening tool for assessing depression in stroke patients.

Other Factors which might Influence Quality of Life

Other variables which may have a bearing on a patient's quality of life were also measured as follows:

Socio-demographic and stroke-related variables

Socio-demographic information was obtained from the participants using the Demographic Data Form. Items were selected from previous studies that correlated with the possible predictors of quality of life being examined in this study. Age, gender, marital status, education, income, and living arrangements were identified in the literature as risk factors for quality of life after stroke and were thus potential intervening factors in this study. In addition to socio-demographic variables, medical and stroke-related information was also obtained using the Neurological Status Form. This form contains items describing stroke type, the site of brain damage, and specific neurological symptoms experienced post-stroke.

Data Analysis

Appropriate descriptive statistics were used to report demographic data. Percentage and range for nominal data and mean and standard deviation for interval data were used to describe participants on QOL, the five possible predictors of QOL, and on socio-demographic and neurological factors. Relationships between quality of life and possible predictor variables, that were all considered interval data, were described individually using Pearson's r and analyzed for statistical significance using the t-test.

Means and analysis of variance or simple independent t-tests, or Pearson r and t-test, were used to examine the individual influence of intervening variables on quality of life. Stepwise multiple regression analysis was used to determine the amount of variance in quality of life that was explained by the possible predictor and intervening variables which were significant at the univariate level. That is, stepwise multiple regression identified the variables that predict quality of life after stroke and their relative importance. Data were analyzed using the Statistical Package for Social Sciences (SPSS, 1993) with the conventional alpha level of .05.

CHAPTER V. RESULTS

The results of the study are reported in four sections: 1) summary description of the sample characteristics, 2) description of quality of life scores, 3) observed relationships among the variables (e.g. socio-demographic characteristics) as well as their relationship to quality of life, 4) findings of a step-wise multiple regression analysis that identifies the variables that best predict quality of life after stroke and each variable's relative importance.

Study Sample

The initial study sample consisted of 55 first-time stroke survivors who were discharged between 1993 and 1995. Of these 55, 50 were able to fully participate in the data collection process. Of the 5 who were excluded from the study, 1 participant refused to complete the social support questionnaire, and 4 participants scored below 24 on the MMSE, which indicated severe cognitive deficits. Study participants' scores on the MMSE ranged from 24 to 30 (M=27.3, SD=2.10).

Sample Characteristics

Socio-demographic Characteristics

Characteristics of these stroke survivors' age, education, and gender were similar to participants in other stroke studies (Ahlsiö et al., 1988; de Haan et al., 1995; King, 1990; Viitanen et al., 1988). The mean age of the final sample at the time of the data collection was 75 years (SD=6.08 years, Range=63-86 years), with 8% under 65, 44% from 65-74 years, and 48% were 75 years and older. The vast majority of the participants was caucasian (92%). Twenty nine (58%) participants were male, and 21 (42%) participants were female. The majority (68%) of participants were married and lived with their spouse or another family member. Fifteen (30%) participants were widowed, and 16 participants (32%) lived alone. Thirteen participants (26%) had post-secondary education, and at the other end of the scale, 18 participants (36%) had only elementary or junior high school education. The educational level of the study sample is similar to the Canadian seniors' educational characteristics surveyed in 1991 by the Statistics Canada (Norland, 1994). According to this 1991 census (Norland, 1994), only 25.6% of those aged 65 years or older had post-secondary education, and 36.9% had post-elementary education (grade 9 or higher). The vast majority of participants (73.4%) had incomes between $20,000 to $40,000 per year or more. Table I provides further information on socio-demographic variables.

TABLE I

Socio-demographic Characteristics of 50 Stroke Survivors

Characteristics	Number	Valid Percent
Age:		
Mean 74.6		
Range 63-86		
Younger than 65	4.0	8.0
65 or older	46.0	92.0
Race:		
Caucasian	49.0	96.0
Black	1.0	4.0
Gender:		
Male	29.0	58.0
Female	21.0	42.0
Marital Status:		
Married	30.0	60.0
Widowed	15.0	30.0
Divorced	3.0	6.0
Never Married	2.0	4.0
Education:		
Graduate Degree	5.0	10.0
Undergraduate Degree	8.0	16.0
Some College Training	9.0	18.0
High School Diploma	6.0	12.0
Partial High School (grade 10-11)	4.0	8.0
Junior High School (grade 7-9)	14.0	28.0
Less than 7 Years Education	4.0	8.0
Income:		
Less than $19,999 per year	13.0	26.5
$20,000 to 39,000 per year	25.0	51.0
$ 40,000 or more per year	11.0	22.4
Living Arrangement:		
Alone	16.0	32.0
With Spouse	30.0	60.0
Living with Parents/Relatives	3.0	6.0
With Hired Attendants	1.0	2.0

Illness-related Characteristics

Twenty-seven (55.1%) participants had experienced a right brain lesion, while 21 (42.9%) participants had experienced a left brain lesion. One participant had experienced a brain stem lesion. The relatively high number of right brain lesions was not unexpected, because the exclusion criteria related to aphasia eliminated many participants with left brain lesions. Regarding stroke type, the majority of the survivors in this sample had suffered from infarcts (73.5%), whereas 7 participants (14.3%) had suffered from hemorrhages. For six participants, stroke types were unknown or incompletely described. Aphasia was present in only 2 participants. Comorbid medical conditions that were frequently reported by the participants were hypertension, cardiovascular problems, arthritis, diabetes, and COPD. Table II provides further information on Illness-related variables.

TABLE II

Illness-Related Characteristics of 50 Stroke Survivors

Characteristic	Number	Valid Percent
Type of Stroke:		
Infarct	36.0	73.5
Hemorrhage	7.0	14.3
Undetermined	6.0	12.2
Site of Brain Lesion:		
Right Hemisphere	27.0	55.1
Left Hemisphere	21.0	42.9
Brain Stem	1.0	2.0
Language Deficit:		
No deficit	48.0	96.0
Aphasia	2.0	4.0
Comorbid Medical Conditions:		
Hypertension	26.0	32.5
Cardiovascular	18.0	22.5
Arthritis	11.0	13.8
Diabetes	11.0	13.8
COPD	6.0	7.5

Quality of Life & Its Observed Correlations to Possible Predictor Variables (including intercorrelations among study variables)

Quality of life Scores

The overall QLI scores ranged from 12.1 to 22.6 with a mean of 18.0 (SD= 2.5). The possible range of overall QLI and subscale scores is 0 to 30. This mean (M= 18.0) was lower than those of other stroke studies (Ferrans, 1990a; King, 1990). The mean subscale scores were also computed. Summary statistics for the QLI scores are presented in Table III.

1). Health and functioning subscale: this domain's scores ranged from 4.5 to 28.9 with a mean of 17.8 (SD= 6.1). This mean score was the lowest of the four subscales.

2). Socioeconomic subscale: in this subscale scores ranged from a minimum of 8.4 to a maximum of 30 with a mean of 23.2 (SD=4.4). 3). Psychological and spiritual subscale: this subscale's mean was 21.5 (SD=5.9). Scores for this scale ranged from 2.5 to 30. 4). Family subscale: Scores for this domain ranged from 3 to 30 and had the highest mean of 24.9 (SD=6.4). Similar figures were recently reported by King (1995) who found that the mean subscale scores of the QLI ranged from 21.5 (health & functioning) to 26.9 (family). Descriptive statistics on the QLI scores are provided in Table III.

TABLE III

Descriptive Statistics on Quality of Life

Dimensions	Mean	Standard Deviation	Range
Health & Functioning	17.8	6.1	4.5-28.9
Socioeconomic	23.2	4.4	8.4-30.0
Psychological/Spiritual	21.5	5.9	2.5-30.0
Family	24.9	6.4	3.0-30.0
Overall Score	18.5	2.5	12.1-22.6

The possible weighted scores of the QLI range from -15 (lowest) to +15 (highest). Weighted item scores ranged from the lowest of -1.1 (health status) to the highest of 11.6 (home). Further information on the weighted QLI item scores is provided in Table IV.

TABLE IV

Ranked Weighted Quality of Life Items

Ten highest weighted items	Score*	Ten lowest weighted items	Score
Home	11.61	Amount of Stress in Life	2.16
Family Happiness	10.36	Ability to Get Around	1.88
Standard of Living	10.23	Usefulness to Others	1.75
Children	10.00	Amount of Pain	1.16
Neighborhood	9.68	Ability to Do Things for Yourself	1.13
Friend	9.37	Ability to Go Places Outside Home	.17
Emotional Support	9.10	Not Having a Job	-.08
Financial Independence	8.58	Sex	-.61
Amount of Control	8.02	Ability to Travel	-.83
Spouse	7.91	Health	-1.07

* Scores range from a minimum of -15 to a maximum of +15

Table V provides summary statistics (e.g., means) for possible predictor variables obtained using five standardized measures. In addition, Table VI provides intercorrelatons among the independent variables as well as their bivariate correlations to the overall quality of life score.

TABLE V

Descriptive Statistics on Possible Predictor Variables Measures

Instrument	Mean	Standard Deviation	Range
Functional Independence Measure	104.7	17.2	63-126
CES-D Scale	12.2	7.9	0-37
Frenchay Activities Index	31.2	10.0	9-56
Perceived Health Status	3.3	0.86	1-5
SSIPAD			
PQUAL (5-23)*	20.8	2.2	13-23
TOTQUAL (15-69)*	55.2	9.9	33-69

TABLE VI

Intercorrelational Matrix among Possible Predictor Variables & QOL

	FIM *(BADL)*	CES-D *Depression*	PHS *Health Status*	FAI *(IADL)*	SSIPAD *Personal Quality*	SSIPAD *Total Quality*
QOL	**.46****	**-.50*****	**.48*****	**.41****	**.44****	**.33***
FIM		**-.35***	**.46****	**.68*****	.12	**.30***
CES-D			**-.56*****	-.27	**-.35***	**-.30***
PHS				**.50*****	.25	.20
FAI					.22	.26
SSIPAD *personal quality*						**.33***

*p < .05
**p < .01
***p < .001

Functional Status (BADL & IADL)

Basic activities of daily living (BADL) was measured using the FIM. The possible total score ranges from 18 to 126, with the higher scores indicating more independence in BADL. FIM scores ranged from 63 to 126. The mean FIM score of 104.7 (SD=17.2) indicated that on average this study sample was highly independent (modified independence)[4] in their basic activities of daily living. This mean score exceeded that of the norm (M= 87, SD= 25.6) which was based on 15,151 stroke patients discharged from a rehabilitation program in 1991 (Granger & Hamilton, 1993). The mean score found for the men (M=104.5, SD=16.4) matched that of the women (M=105.0, SD=18.6). The frequency distribution for the FIM values was negatively skewed, since almost two thirds of the sample had a score above 90/126. When comparing the average FIM scores upon admission (M=80.8, SD=22.1) and discharge (M=104.6, SD=18.0), a significant increase in functional status was found.

Increased functional status was associated with higher quality of life. The FIM (BADL) scores were positively and significantly associated with the overall quality of life (r=.46, p=.001). FAI (IADL) scores ranged from 9 to 56 with a mean of 31.2 (SD=10.3). The association between the FAI scores and overall quality of life was also positive and significant (r=.41, p=.003).

In addition, the FIM scores showed significant positive relationships with perceived health status (r=.46, p=.001), and with FAI (r=.68, p=.000). Therefore, higher functional

---

[4] Modified Independence if one or more of the following is present: the activity requires an assistive device; the activity takes more than reasonable time; there are safety considerations (Data Management Service of the Uniform Data System for Mediacal Rehabilitation and the Center for Functional Assessment Research, 1994).

status was correlated with more positive perceptions of health status in this group of stroke survivors.

Besides correlating with PHS and FAI, the FIM scores were negatively and significantly correlated with the CES-D scores (r=.-35, p=.013). This negative relationship indicates that an increased dependency in daily activities was correlated with greater depression. The FIM scores did not differ significantly by age, gender, marital status, side of brain lesion, or stroke type.

Post-stroke Depression

The average score on the CES-D was 12.2 (SD=7.93), which was substantially above the upper limit of the norm based on 2,514 adults in the United States (M=9.3, SD=8.6) (Radloff, 1977). The possible range of scores is 0 to 60, with the higher scores indicating more depression. Scores ranged from 0 to 37; hence, the frequency distribution of the CES-D scale values showed a notable dispersion. Sixteen participants (32%) scored at or above 16, which indicates clinical depression.. Thus, the prevalence of post-stroke depression in this study sample was 32%. This finding is similar to those of other stoke studies in the literature (King, 1990; Niemi et al., 1988) but contrasts to that of the general population (2,514 adults) (Radloff, 1977). 16% of the participants interviewed lived alone in their homes. The mean score for this subgroup was 11.38 (SD=6.0). Thus, in our cases living alone did not worsen the depression.

The relationship of the CES-D scores to overall quality of life was negative and significant (r=-.50, p=.000). Thus, lower CES-D scores were associated with higher overall quality of life scores: those who were more depressed reported a lower quality of life. When the CES-D scores were dichotomized as present or absent, the average quality of life score for the non-depressed group was higher than the depressed group (M=18.16 versus M=17.38). Further, the scores on the CES-D were associated negatively and significantly with age (r=-.3.0, p=.034), functional status (r=.35, p=.013), perceived health status (r=-.50, p=.000), and perceived quality of social support (r=-.30, p=.036). These negative relationships indicated that lower functional status, poor quality of social support and negative perceptions of health status were correlated with greater depression. Further, younger ages were also associated with higher levels of depression. Depressed and non-depressed groups were compared across the demographic and clinical variables. Overall gender, site of lesion, and stroke type did not differentiate groups as to severity of depression.

Perceived Quality & Quantity of Social Support

The SSIPAD measures the perceived social support from five sources, each with two components, quality and quantity dimensions, as cited earlier. Scores were calculated by summing three source categories (a single significant personal relationship, close friends and family members, and community individuals) in this study.

The TOTQUAL[5] scores ranged from 33 to 69 with an average of 55.2 (SD=10.0). Possible scores ranged from the lowest of 15 to the highest of 69. This indicated that the study sample had a relatively high quality of social support (higher scores indicate greater quality of social support). The TOTQUAL scores were associated significantly and positively with the overall quality of life scores (r=.33, p=.020). Thus, a greater quality of perceived support was related to higher quality of life. In addition, the overall QOL scores

---

[5] A total qualitative score of the SSIPAD was generated by summing the three quality scores (personal, family & close friends, and community individuals)

were also positively and significantly related to PQUAL[6] (r=.44, p=.001) and CQUAL[7] (r=.38, p=.019). The TOTQUAN[8] scores ranged from 6 to 20 with a mean of 14.2 (SD=3.2). Possible scores ranged from 3 to 24, indicating a relatively low quantity of social support. The TOTQUAN scores were not significantly correlated with the overall quality life scores (r=-.01, p=.50). Hence, a greater amount of social support was not related to higher quality of life.

The most frequently reported source of informal support was from children (32%), spouse (25%), and friends (22%). In addition, the most frequently identified types of support were emotional support (52%) followed by instrumental support (41%) and informational support (7 %).

Perceived Health Status

With respect to participants' perceptions of their health status, twenty-one (42%) participants reported "good" or "excellent," but more than half (58%) of the sample reported "fair," "poor," or "very poor." In this group of stroke survivors, negative responses outnumbered positive responses (58% vs. 42%). Positive responses did not decrease with age within this study sample. These findings are significantly different from the Canadian population where 75% of seniors (65 years and older) reported "good" or "excellent" health (Norland, 1994).

---

[6] A subtotal qualitative score of the SSIPAD from a close personal relationship.

[7] A subtotal qualitative score of the SSIPAD from individuals in the community.

[8] A total quantitative score was generated by summing the three quantity scores (personal, family & close friends, and community individuals)

Perceived health status was positively and significantly correlated with the overall quality of life scores (r=.48, p=.000). Perceived health status had a moderately strong relationship with quality of life. Thus, the overall quality of life scores increased as the positive health status responses increased. Similarly, perceived health status was also directly related to a single quality of life item on satisfaction with "life in general". A greater proportion of participants who reported "good" or "excellent" health was satisfied with life, whereas all of the participants who reported "fair" or "poor" health were very dissatisfied with life. As expected, the vast majority (95%) of participants who reported "good" or "excellent" health was highly independent in BADL.

Quality of Life & Its Observed Correlations to Intervening Variables (including intercorrelations among study variables)

Age

The relationship of age to quality of life was not significant (r=.28, p=.051). Further, age did not correlate with most of the study variables. Nevertheless, age was negatively correlated with the CES-D scores, as mentioned earlier. Thus, younger age was related to greater depression. In addition, age was correlated positively and significantly with PQUAL (r=.31, p=.029) and CQUAL (r=.39, p=.018). Therefore, older age was correlated with greater support from a single significant personal relationship or individuals in the community.

Gender

On average, males had a mean quality of life score of 18.4, and females have a mean quality of life score of 17.6. There were no significant gender-based differences in quality of life scores, t(48) = .96, p>.05. The differences in mean quality of life scores and the dichotomized categories of stroke type t (47)=-.34, p=.74 and lesions of location t (47)=-1.96, p=.60 were not statistically significant.

Marital Status

The differences between mean quality of life scores and the different categories of marital status were statistically significant when an analysis of variance (ANOVA) was performed F (3, 46)=3.2, p=.03. However, when a post-hoc Scheffé test was computed, no two groups were significantly different at the .05 level. The largest difference, though statistically insignificant, was between those who were married (M=18.6) and those who were divorced (M=15.0). This variable was dichotomized as "1" for married and "-1" for non-married, for multiple regression analysis. A positive and significant relationship between this dummy variable (contrast vector) and the overall quality of life scores (r=.29, p=.043), though small, indicated that being married was associated with higher quality of life.

Living Arrangement

ANOVA was also performed to investigate the differences between mean quality of life scores and the different categories of living arrangements. A statistically significant difference was found: F (3, 46) =3.0, p<.05. However, when a post-hoc test was computed, no two groups were significantly different. This variable was also dichotomized as "1" for living alone, and "-1" for not living alone, for multiple regression analysis. The relationship between this dichotomized variable and quality of life was negative but was not statistically significant (r=-.16, p=.272).

Income

Income was positively correlated with quality of life (r=.30, p=.041). Thus, a higher income was associated with higher quality of life. When mean quality of life scores for the different categories of income were compared, participants who had an annual income of $40,000 or more had the highest mean quality of life score (M=19.4). When the level of income was compared with satisfaction with life, less than 20% of participants reported satisfaction with life had incomes of less than $19,999 per year. About 80% of the participants who reported satisfaction with life had incomes above $20,000 per year.

Education

In addition, education was not significantly associated with QOL (r=.24, p=.087). Nevertheless, in this study, the mean quality of life score for the participants with master's or doctoral degrees was significantly higher than that of participants who had fewer years of schooling. There was no evidence, however, that the mean QOL score of participants with lower college or university degrees differed either from that of participants with high school diplomas or from that of participants with junior high school diplomas. Table VII provides intercorrelations between the intervening variables and the overall QLI scores.

TABLE VII

Intercorrelation Matrix between Intervening Variables & QOL

	Age	Gender	Married Status	Education	Income	Living Arrangement	Lesion	Type
QOL	.28	-.14	**.29***	.24	**.30***	-.16	-.05	-.24

* p <.05

Multivariate Relationships of QOL to Possible Predictor & Intervening Variables

A stepwise multiple regression was performed to determine the best predictors of quality of life. The variable entry and removal criteria were set at $p<.05$. Study variables showing a statistically significant, bivariate correlation with the QLI were simultaneously considered for selection. As a group, depression, marital status, quality of social support, and functional status (IADL) were highly significant indicators. It is not uncommon for a small number of variables to account for most of the variation in the dependent variable (Volicer, 1984). Depression (CES-D) was entered into the equation first and accounted for 32 % (Adjusted R Square = 30%) of the variance in quality of life. When all remaining variables were entered and the effect of depression removed, marital status (Adjusted R Square = 15%) was selected in the second step. Quality of social support (Adjusted R Square = 9.4%) and functional status (Adjusted R Square = 6.2%) were the next predictors added to the final equation. Together, these four predictors explained 60.1% of the variance in quality of life. Table VIII provides a summary of the stepwise multiple regression analysis.

TABLE VIII

Multiple Regression Analysis of Quality of Life

Variables	Adjusted R Square *Total*	Adjusted R Square *Change*	t
1. CES-D (depression)	.299	*	-3.941+++
2. Marital Status (Being Married)	.446	.147	3.125++
3. Social Support (Personal)	.539	.093	2.724+
4. Functional Status (IADL)	.601	.062	2.420+

+ $p<.05$
++ $p<.01$
+++ $p<.001$

CHAPTER IV. DISCUSSION

The objective of this cross-sectional study was to assess the level of overall quality of life of 50 community-based stroke survivors and to determine the relationships between functional status (BADL & IADL), social support, perceived health status, depression, and overall quality of life. The secondary purpose of the current study was to examine the possible influences of eight other intervening variables (age, gender, marital status, income, education, living arrangement, stroke type, & localization of lesion) on quality of life. This chapter consists of a discussion of the significant findings of the study, the assumptions and limitations of the study, its implications for rehabilitation, and recommendations for future research.

Overall QOL & Its Correlations with Study Variables

Overall Quality of Life & Weighted Scores

Results of this study indicate relatively low overall quality of life for this sample of 50 community-based stroke survivors, which is not surprising given the devastating impact of stroke on an individual's performance. Depending on the severity and mechanism of the stroke, stroke survivors frequently suffer some degree of permanent, residual impairment to their neurological, physical, psychological and social functions. Consequently, the occurrence of a stroke often results in negative life changes for the stroke survivor, including increased dependency on others for activities of daily living, alternation in mood, and disruption in social interaction with family members (Biegel et al., 1991). Results from the present study are consistent with reports by other investigators (Ahlsiö et al., 1984; Kelly-Hayes, 1995; Vittanen et al., 1988) who found that the majority of stroke survivors followed for up to 4 years reported a significant reduction in their quality of life. When the mean quality of life scores were compared across different studies, the mean quality of life score for the present sample was somewhat lower than the mean obtained by King (1990) for stroke survivors with a relatively similar duration of stroke (1-3 years post-rehabilitation), and markedly lower than the means obtained by Ferrans (1990a) for patients with cancer. The health and functioning subscale of the QLI generated the lowest mean subscale score. This finding was certainly not unexpected because close to two thirds of stroke survivors often suffer some degree of physiological and psychosocial difficulties following stroke (Canadian Heart & Stroke Foundation, 1996).

The highest weighted scores (high positive scores) are obtained through combinations of high satisfaction/high importance responses, and the lowest (negative & low positive scores) are obtained by high dissatisfaction/high importance responses (Ferrans & Powers, 1985; king, 1990). The low weighted scores represent a disparity between satisfaction and importance responses. Weighting with low importance responses produces middle range scores (Ferrans & Power, 1985; King, 1990). When weighted score items were ranked and compared, the lowest weighted quality of life items were related to health and functioning (See Table IV). Additionally, the highest weighted quality of life items were linked with family and socioeconomic items (See Table IV). Similarly, King (1990) also reported that satisfaction with family items were related to a high overall quality of life for 86 stroke survivors with 1-3 years post-rehabilitation.

Some QLI items that ranked low in weighted scores are associated with physical health (e.g., "ability to get around", "ability to do things"). In addition to physical health items, dissatisfaction with productivity (e.g., "not having a job", "usefulness to others") also contributed to low overall quality of life. Nearly half of the study sample reported dissatisfaction or slight satisfaction in response to a single quality of life item on satisfaction with "their usefulness with others". Considering the age and life expectations of the study sample, it is highly likely that these elderly participants may associate the meaning of the word, "usefulness" or "productivity" with having paid employment. Further, the vast majority of the participants had retired, and a subsample of 42% reported dissatisfaction or slight satisfaction with leisure time activities. This finding is congruent with other stroke studies where a decline in leisure activities was also reported (Labi et al., 1980; Niemi et al., 1988; Viitanen et al., 1988; Widén-Holmqvist, Pedro-Cuesta, Holm, Sandström, Hellblom, Stawiarz, & Bach-y-Rita, 1993). A recent report indicates that participation in leisure was positively associated with increased life satisfaction (Widén-Holmqvist et al., 1993). An effective rehabilitation and follow-up intervention should focus on identifying those environmental factors that either foster or impede stroke survivors' participation in their leisure activities. This kind of focus on the contributions of leisure on quality of life would allow stroke survivors to redefine the meaning of their optimal productivity and to explore new avenues. In addition, the identified items related to the lowest quality of life in this study have potential to precipitate psychological distress and subsequently negatively influence quality of life following stroke (King, 1990). This finding implies that provision of a long-term follow-up of physical and psychosocial management to stroke would be beneficial. However, the efficacy of these kinds of interventions such as outpatient physical rehabilitation and post-stroke psychological counseling needs to be explored further.

As discussed earlier, the identified weighted items to the highest quality of life were related to family and socioeconomic status. This finding further validates the importance of diversified, close informal networks (e.g., child, friend, neighbor, and spouse) in fostering the person's quality of life following stroke. In this study, family caregivers represent a large segment of social support, and perception of adequate support from a key personal relationship (usually with spouse) was related to higher quality of life. Furthermore, it is commonly acknowledged that post-stroke family adjustment is a strong predictor of successful rehabilitation. Consequently, in order to help families continue in a supportive role, early development and implementation of family support initiatives in rehabilitation are of paramount importance to assist families in developing better coping strategies.

The responses to some of the quality of life items such as satisfaction with "sex" and "job" were frequently omitted by the respondents. Considering the age and life experiences of the participants in this study, these items should be modified in future studies. For example, the quality of life item "satisfaction with sex" should be changed to "satisfaction with intimate relationships." Further, the quality of life item "satisfaction with your faith in God" should also be modified to "satisfaction with spiritual life". This approach may improve the cultural and societal sensitivity of the index.

Post-stroke Depression

In the present study, participants who reported a poorer quality of life experienced greater depression. Further, depression was the single best predictor of quality of life (B=-.57, p=.0004), and it contributed as much as 30% (Adjusted R Square) of the variance in quality of life. This finding on depression is notably similar to the report by King (1990), who also found depression to be the strongest predictor of quality of life. Further, other stroke studies also reported the importance of depression to measurements of quality of life (Ahlsiö et al., 1984; Kameyama, Udaka, Mezak, Sawada, Seriu, Shindo & Nishitani, 1990; Kaun, 1990; Niemi et al, 1988). This finding on the relationship of depression to quality of life further validates the view that psychological distress such as depression significantly lowers quality of life following stroke.

Post-stroke depression was a stronger determinant of quality of life than functional status in this sample. This result is consistent with findings obtained by other investigators who reported that depression and anxiety decrease quality of life as much as (or more than) physical disability (Ahlsiö et al., 1984; King, 1990). This finding provides further evidence that there are other important variables besides functional status which affect quality of life following stroke.

The prevalence of post-stroke depression in this sample was 32%. Similar prevalence rates ranging from 30% to 41% have been obtained by other studies of post-discharge stroke survivors (Fibel & Springer, 1982; Kaun, 1990; King, 1995; Shinar et al., 1985; Santus, Ranzenigo, Caregnato & Inzoli, 1990). Other studies of stroke survivors also observed that rates of post-stroke depression change over time (Egelko, Simon, Riley, Gordon & Ruckdeschel-Hibbard, Diller, 1989; Feibel & Springer, 1982; Robinson, Bolduc, & Price, 1987; Robinson & Price, 1982). The latter (Robinson & Price, 1982) observed that the prevalence of depression was greater during the period of 6 months to 2 years post-stroke, compared to that of 2 to 9 years post-stroke. Unfortunately, because of the limitations of the cross-sectional design, this study could not assess changes in the prevalence of depression over time. Nevertheless, the prevalence rate in this sample is consistent with other findings. Depression persists among long-term stroke survivors, and consequently, long-term psychological counseling after discharge from the hospital could be useful.

A significant relationship between depression and quality of informal social support was also observed. Specifically, a higher level of depression was found when informal social support was lacking. This finding is consistent with reports showing a strong association between a low quality of social support and post-stroke psychological distress (Morris, Robinson, Raphael, & Bishop, 1991; Thompson, Sobolew-Schubin, Graham & Janigian, 1989). Morris and colleagues (1991) found that stroke survivors who reported inadequate support from spouses also experienced greater depression. As expected, in this study, depression was not significantly related to all three dimensions (quantity, quality, & source) of social support. Only the quality of social support, particularly from a key personal relationship (usually with a spouse), was significantly related to depression. This finding is consistent with that of Friedland and McColl (1989), who reported that the types of social support that are most influential are supports from a close personal source and supports from individuals in the community. This finding adds further evidence that the perception of social support from key personal relationships may mediate the responses to the life crisis of stroke (Morris et al, 1991). Social support has been shown to act as a buffer against stress in a variety of situations (Cohen & Syme, 1985; Friedland & McColl, 1987). This study did not examine the ways in which social support affects post-stroke depression, but the findings obtained in this study suggest the need for further research in this area.

Married Status

Further, in the multivariate analysis, being married accounted for nearly 16% (Adjusted R Square) of the variance in quality of life. The finding of the significant relationship between married status and quality of life is consistent with that of Osberg, DeJong, Haley, Seward, McGinnis, and Germaine (1988). This positive relationship strongly supports the current view that in general stable marital status, high socioeconomic status, and better education are found to be positively associated with quality of life. These results demonstrate the importance of considering multiple predictors in quality of life studies.

Social Support

Relationships were observed between quality of life and each of the three dimensions (quantity, quality & source) of informal social support in the SSIPAD. In the present study, a greater quality of informal social support was associated with higher quality of life. Specifically, a somewhat higher quality of life was reported by stroke survivors who perceived adequate support from close personal relationships (mostly spousal) and individuals in the community. Further, quality of social support from a close personal relationship accounts for 9.4% (Adjusted R Square) of the variance in quality of life. This positive relationship between QOL and quality of social support confirms the findings of other stroke studies, indicating that persons who report greater social support also report higher quality of life. However, the process by which social support and quality of life influence each other needs further research.

It should also be noted that a higher quantity of social support was not related to higher quality of life. This finding is consistent with the report by Kaun (1990) who, using the quantity dimension of the SSIPAD, reported no significant association between subjective well-being and the quantity of social support. Other studies with different populations have reported that the quality was more important than quantity of social support in predicting quality of life (Fuhrer, Rintala, Hart, Clearman & Young, 1992; Goodenow, Reisine & Grady, 1990, Schulz & Decker, 1985, Smith, 1995).

Functional Status (BADL & IADL)

The relationship of quality of life to both dimensions of functional status (BADL & IADL) were significant at the univariate level. In the current study, participants who were more functionally independent reported a higher quality of life. However, when study variables were analyzed in the multivariate analysis, functional status was not a strong predictor of quality of life. Instrumental activities of daily living (IADL) explains only about 6.2% (Adjusted R Square) of the variance in quality of life (BADL was not even entered into the final equation and thereby did not account for a significant amount of variation in quality of life). This finding suggests that functional status is not a strong determinant of quality of life, and other psychosocial variables need to be considered to more accurately predict satisfactory quality of life in persons who have had a stroke. Recent studies have clearly indicated that stroke survivors reported deterioration in quality of life despite varying levels of functional recovery (Ahlsiö et al., 1984; Fiebel & Springer, 1982; Labi et al., 1980; Niemi et al, 1988; Nydevik et al., 1992; Viitanen et al., 1988).

Furthermore, the relationship between functional status (BADL) and depression, albeit weak, was significant. However, there was no significant correlation between stroke-related variables (side of lesion & stroke type) and depression. These findings suggest that stroke-related variables may not be as influential as functional status (BADL) in determining depression. Other studies have also found no significant correlation between functional status and depression (Kaun, 1990; King, 1990; Robinson & Price, 1982). The weak correlation of depression to BADL, together with the findings from other studies, indicates that physical disability is not the sole determinant of post-stroke depression. Although a significant correlation between depression and functional status (BADL) was obtained, it is not possible to imply a causal relationship. Thompson and colleagues (1989) observed that poor functional status does not precipitate depression. Rather, as frequently cited in the literature, the presence of depression impairs function just as much as impaired function worsens depression (King, 1990; Sadin et al., 1994; Thompson et al., 1989).

Other Correlates of Quality of Life

The intervening variables of age, stroke type, lesion of location, and income did not predict overall quality of life. Age was not significantly associated with quality of life. The relationship between age and QOL further validates the results of some other stroke studies (Ahlsiö et al., 1984; Osberg, et al., 1988; King, 1990), but also contrasts with those of others (Davidson & Young, 1985; Niemi et al., 1988). The respective powers of these studies are different. This difference may explain the discrepant results of this study. With a slightly larger sample (and thus a greater power), a value of .28 might have been found to be significant. In addition, the difference in sampling may also explain this contradictory result. The stroke survivors in the present sample were predominantly older than 65 years, whereas proportionately, a larger number of stroke survivors were younger than 65 years of age in the other studies. It is likely that younger stroke survivors would experience more dramatic changes in their lives following stroke, and therefore would report lower satisfaction with their lives. However, the basis of this relationship requires further study.

No significant relationship was reported between stroke-related variables and quality of life, just as none was reported by de Haan and his associates (1995). However, Niemi and his colleagues (1988) found that subarachnoid hemorrhage caused less deterioration in quality of life compared to brain infarction. However, stroke-related variables alone did not fully explain the variation in quality of life in their study.

In addition to these negative findings, there were positive findings that deserve discussion. As expected, being married or having a higher income were all associated with higher quality of life. Nearly eighty percent of the participants who reported satisfaction with life had incomes above $20,000. A possible sociological explanation of this relationship is that having a higher income may provide a greater sense of stability and accomplishment in one's life.

Assumptions and Limitations

This research design assumes, on the strength of sampling criteria, that the study sample associated with the Glenrose Rehabilitation Hospital is representative of stroke patients treated at the GRH, but it may not be representative of the post-stroke population living in the community. The sample used for this study was a convenient group of stroke survivors whose medical status and cognitive and communication abilities permitted participation in the interview methods employed. The generalizability of the study results from this small, relatively homogenous sample is reduced by the entry criteria for study participants. Further, the internal validity of the study results is affected by the refusals of large number of eligible stroke survivors to participate in the study. Comparisons of socio-demographic and neurological status variables between participants and non-participants at discharge may help one to detect any systematic sampling bias. However, demographic and neurological information on non-participants could not be retrieved from the hospital records due to ethical considerations.

Since this study employs a cross-sectional design, description and analysis of changes in quality of life and all other variables among stroke survivors at different phases of their convalescence were not provided, and causality in some instances (e.g., quality of life and depression) could not be established. However, because of limited research on quality of life for stroke survivors, the cross-sectional design was useful for identifying correlations which can be used as a basis for future longitudinal studies. In such studies, for example, whether poor quality of life worsens depression or the presence of depression lowers quality of life can be further examined.

Implications for Rehabilitation

Previous literature suggests that the specific nature of post-stroke disability is a combination of physical, psychological and social consequences and resources. However, physical restoration alone has long been the primary focus in stroke rehabilitation. The presence of psychosocial dysfunction has always been acknowledged, but has been little emphasized; its possible influence on quality of life has not yet been fully explored. Since the recent shift to defining health as a socio-ecological concept, rehabilitation programs have seriously considered the complex interactions between individuals and their social and physical environments. Rehabilitation professionals have thus been challenged to integrate environmental concerns into clinical practice.

The roles of socio-demographic variables, stroke-related variables, functional status, perceived health status, post-stroke depression, and social support in determining quality of life after stroke are important areas which require further research. Thus, with the understanding that quality of life and stroke recovery are complex phenomena, this study provided a better understanding of these dynamic factors. In considering the significant findings from this study, rehabilitation professionals take into account the following factors when offering an intervention in rehabilitation settings:

1) On average, the overall quality of life for community-based stroke survivors in this study was relatively low despite a reported high ADL-capacity. These survivors 1-3 years post-stroke reported the lowest satisfaction with life, but placed high importance on quality of life items related to physical health, productivity and stress. Thus, it would be vital to provide a long-term follow-up of physical and psychosocial interventions (e.g., psychological counseling) to stroke survivors during post-discharge periods.

2) Findings from the current study indicate that functional status is not as strong a predictor of quality of life as psychosocial variables such as depression and social support. Among the study variables measured, depression, marital status, and social support were found to be strong predictors of quality of life in the present study. This suggests that adjustment to stroke involves much more than physical function. In other words, improvement in functional status is important, but is not a sufficient condition for successful rehabilitation. Thus, to more effectively facilitate improved quality of life, rehabilitation programs need to place more emphasis on psychosocial issues that affect stroke survivors' life as a whole.

3) There is evidence that even 1-3 years after discharge from the hospital, stroke survivors continue to suffer from depression long-term and may benefit from a long-term

intervention to counter such psychological distress as depression. Rehabilitation professionals should therefore incorporate a psychological assessment and counseling into their practice. Evaluating patient's emotional responses to a stressful event such as a stroke is critical in understanding its potential effects on their lives (Popovich, 1992). These findings on depression suggest that psychological distress is more important than physical status in determining the quality of long-term stroke survivors' lives. Hence, rehabilitation professionals should integrate these psychological factors into programme planning and intervention to better facilitate patients' adjustment following stroke. Further, a complete adjustment to stroke will probably not happen during the brief period of stroke rehabilitation. Therefore, when providing psychological intervention in rehabilitation, emphasis should be placed on long-term intervention that includes pre/post-discharge counseling. This is extremely important because 32% of the participants in the present study were apparently depressed and may need assistance in coping more effectively with psychological distresses. Thus, early post-discharge counseling could help stroke survivors to effectively deal with psychological distresses beyond hospitalization. Long-term follow-up is advisable as it may help prevent emotional breakdowns and subsequent decreased quality of life. Although individual and group counseling or intervention is recommended for adaptation and management of the stresses associated with stroke, the effectiveness of such approaches should be further investigated. Such research is particularly important in determining the type and timing of interventions that are most appropriate for stroke survivors who are at risk of experiencing psychological distress after stroke.

4) The two strong predictors of quality of life (depression & social support) in this study represent stroke survivors' perceptions of their life situations. This finding indicates that individual perception is integral to the concept of quality of life. Thus, in rehabilitation, the subjective experiences of stroke survivors, rather than the objective aspects of their lives, should become a judge of satisfactory quality of life following stroke. Therefore, in designing an effective post-stroke rehabilitation intervention, rehabilitation professionals need to recognize that stroke survivors must be involved as partners in the process and be allowed to identify their own problems and plan their solutions.

5) Consistent with findings from earlier studies, family members (mostly spouses & children) were frequently identified as the most important sources of social support. Additionally, the vast majority of participants in this study reported that they were not capable of reciprocating the support they received from their family members. Consequently, in order to help families continue in a supportive role, early development and implementation of family support intervention in rehabilitation is of paramount importance to assist family caregivers in developing new coping strategies or strengthening coping skills. The events surrounding the stroke are seen as the stressors which place the stroke survivors and their caregivers at risk for negative health outcomes. Many studies have found that a significantly high number of caregivers experience physical, emotional, and social burdens (Beckingham, 1993). Moreover, caregivers encounter various problems, including the need for physical relief from caregiving, the need for instrumental assistance, and problems with work commitments which conflict with caregiving responsibilities (Beckingham, 1993). Chappell (1992) states that emotional burden, along with economic constraints, is a major

factor in the decision to institutionalize a disabled elderly family member. The families of stroke survivors should therefore have access to help during a practical crisis. Consequently, public health policies and programs should complement the helping role of the family and acknowledge the dependency of stroke survivors upon the public sector as well as the significance and persistence of the natural family helping network (Chappell, 1992; Glass & Maddox, 1993; Sauer & Coward, 1985; Stroker, 1983). Groups of caregivers can advocate for home care polices which complement the family through a balance of formal and informal support systems, that is, policies which minimize the financial and service burdens of caregiving and maximize the use of available support options, such as respite care programs (Chappell, 1992; Sauer & Coward, 1985). These services would provide primarily practical support for the caregivers. These programs are valuable because they give the family members the opportunity to take care of their relatives at home without becoming physically and emotionally exhausted.

6) QLI questionnaire was found to be appropriate for this group of stroke survivors suggesting its future application in occupational therapy practice and research. Because of its ease of application with stroke survivors, this index can be used to identify those aspects of life that are of greatest of concern to patients. Results could provide a baseline for evaluating and planning interventions designed to improve quality of life.

Quality of life has been recently recognized as an important outcome criterion for health care professionals. Nevertheless, the major emphasis of stroke outcome research has been on functional recovery, and as a result, studies investigating the quality of life of stroke survivors have been very limited. Thus, this study was aimed at identifying those factors that affect the quality of life of stroke survivors. Such knowledge is vital if the current rehabilitation is to enhance the quality of their lives in the community.

Recommendations for Future Research

The present study investigated the relationship of a limited number of psychosocial variables to quality of life. The findings further validated the multi-dimensional aspects of quality of life. Future studies can further contribute to the concept of quality of life by focusing on quality of life in the context of other environmental elements (cultural and physical) in a person's life. Because of the limitations of the cross-sectional design, the description and analysis of change in depression and changes in types of social support available to stroke survivors could not be investigated. A longitudinal study of the same factors could identify the most appropriate and effective timing of different types of interventions. Additionally, because social support has been shown to act as a buffer against stress in a variety of situations, research is required to determine the process by which social support and quality of life influence each other.

As well as evaluating the quality of life of stroke survivors, the effects on the patient's recovery of his/her family's adaptation to stroke should be further investigated. These kinds of longitudinal studies would provide valuable information on the effects of long-term caregiving and their impacts on the long-term well-being of stroke survivors. Additional study is required to determine the differential impact of social support on change in quality of life for persons with stroke.

This study assessed the level of quality of life in a cross-section of persons with stroke living in the community. Since adjustment to stroke-related disabilities is dynamic and long-term, future studies using a longitudinal approach should investigate change in quality of life of post-discharge persons after stroke. Findings from these kinds of longitudinal studies would further increase the comparability across different studies. Additionally a longitudinal study can also further validate the results from previous studies that deteriorated quality of life persisted among long-term stroke survivors.

The socio-ecological concept of health emphasizes that barriers to occupational function are the results of disabling environments. Rehabilitation therapists have thus been challenged to integrate psychosocial concerns into clinical practice. By integrating the socio-ecological concept of health into their practice, rehabilitation therapists can further contribute to the occupational health of stroke survivors. These changes in the field of rehabilitation will not happen smoothly or without conflict. Such changes do, however, represent an alternative and positive vision for the future, a future in which the individuals with permanent disabilities caused by stroke, along with their families, can sustain healthy lifestyles as contributing members of our communities.

REFERENCES

Anderson, C.S., Linto, J., & Stewart-Wynne, E.G. (1994). A population-based assessment of the impact and burden of caregiving for long-term stroke survivors. *Stroke, 26* (5), 843-849.

Anderson, M. P. (1993). *Social support and students with disabilities.* Unpublished master dissertation, University of Alberta, Edmonton, AB.

Ahlsiö, B., Britton, M., Murray, V., & Theorell, T. (1984). Disablement and quality of life after stroke. *Stroke, 15*, 886-890.

Antonucci, T.C. (1990). Social support and social relationship. In R.H. Binstock & L.K. George (Eds.). *Handbook of aging and social sciences* (3rd ed. Pp.205-2227). San Diego, CA: Academic Press.

Becker G.(1993). Continuity after a stroke: Implications of life-course disruption in old age. *Gerontology, 33*,148-158.

Beckingham, A. C. (1993). The family and the aging person. In Beckingham, A. C., & DuGas, B. W. (Eds.), *Promoting healthy aging: A nursing and community perspective* (pp. 267-300). Toronto, ON: Mosby-Year Book Inc.

Biegel, D., Sales, E., Schulz, R., & Rau, M.T. (1991). Caregiving in stroke. In Biegel, D., Sales, E., & Schulz, R. (Eds.), *Family caregiving in chronic illness* (pp. 129-146). London: Sage.

Brocklehurst, J.C., Morris, P., Andrew, K., Richards, B., Laycock, P.(1981). Social effects of stroke. *Social Science and Medicine, 15A*, 35-39.

Calman, K. C. (1989). Definitions and dimensions of quality of life. In N. K. Aaronson & J. Beckmann (Eds.). *The quality of life of cancer patients (pp. 1-9).* New York, NY: Raven.

Canadian Association of Occupational Therapists & Department of National Health and Welfare (1991). *Occupational therapy guidelines for the client centered practice.* Toronto, ON: CAOT.

Chappell, N. L. (1992). *Social support and aging.* Toronto, ON: Butterworths Canada Ltd.

Cohen, J. & Cohen, P. (1983). *Applied multiple regression correlational analysis for the behavioral sciences.* Hillsdale, New Jersey: Lawrence Earlbaum Associates.

Cohen, S., & Syme, L.S. (1985). *Social Support and Health.* Orlando, FL: Academic Press, Inc.

Cohen, S., & Wills, T.A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin, 98*, 310-357.

Data Management Service of the Uniform Data System for Medical Rehabilitation and the Center for Functional Assessment Research (1994): *Guide for use of the uniform data set for medical rehabilitation.* Buffalo, NY. State University of New York.

de Haan, R., Aaronson, N., Limburg, M., Hewer, R. L., & van Crevel, H. (1992). Measuring quality of life in stroke. *Stroke, 24*, 320-327.

de Haan, R. J., Limburg, M., Van der Meulen, J. H. P., Jacobs, H. M., & Aaronson, N. K. (1995). Quality of life after stroke: Impact of stroke type and lesion location. *Stroke, 26*(3), 402-408.

Davidson, A., & Young, C. (1985). Repatterning of stroke rehabilitation clients following return to life in the community. *Journal of Neurosurgical Nursing, 17*(2), 123-128.

Duncan, P. W. (1994). Stroke Disability. *Physical Therapy, 74*(5), 399-407.

Duncan, P. W., & Badke, M. (1987). *Stroke rehabilitation: The recovery of motor control.* Chicago, IL: Year Book Medical Publishers Inc.

Eckenrode, J., & Gore, S. (1990). *Stress between work and family.* New York: Plenum.

Egelko, S., Simon, D., Riley, E., Gordon, W., Ruckdeschel-Hibbard, M., & Diller, L. (1989). First year after stroke: Tracking cognitive and affective deficits. *Archives of Physical Medicine and Rehabilitation, 70*, 297-302.

Epp, J. (1986). *Achieving health for all : A framework for health promotion.* Ottawa : Minister of Supply and Services.

Evans, R.L. Bishop, D.S. & Ousley, R.T. (1992). Providing care to persons with physical disability: Effect on family caregivers. *American Journal of Physical Medicine and rehabilitation, 71*(3), 140-144.

Evans, R.L., & Northwood, L.K. (1983). Social support needs in adjustment to stroke. Archives *Physical Medicine and Rehabilitation, 64*, 61-64.

Evelyn, L.T., & Chui, H.C. (1987). The Modified Mini-Mental State Examination. *Journal of Clinical Psychiatry, 48*(8), 314-317.

Fallowfield, L. (1990). *The quality of life : The missing measurement in health care.* London:Souvenir Press.

Farzan, D.T. (1991). Reintegration for stroke survivors: Home and community considerations. *Nursing Clinics of North America, 26*(4), 1037-1048.

Ferrans, C. E. (1990a). Development of a Quality of Life Index for patients with cancer. *Oncology Nursing Forum, 17*(3), 15-19.

Ferrans, C. E. (1990b). Quality of life: Conceptual issues. *Seminars in Oncology Nursing, 6*(4), 248-254.

Ferrans, C. E. & Powers, M. J. (1985). Quality of life index: Development and psychometric properties. *Advances in Nursing Science, 8* (1), 15-24.

Ferrans, C. E. & Powers, M. J. (1992). Psychometric assessment of the Quality of Life Index. *Research in Nursing & Health, 15*, 29-38.

Fiebel, J.H., & Springer, C. J.(1982). Depression and failure to resume social activities after stroke. *Archives of Physical Medicine and Rehabilitation, 63*, 276-278.

Folstein, M. F., Folstein, S. E., & McHugh, P.R. (1975). "Mini-Mental State": A practical method for grading the cognitive state of patients for the clinician, *Journal of Psychiatric Research, 12*, 189-198.

Friedland, J., & McColl, M.(1987). Social support and psychosocial dysfunction after stroke: buffering effects in a community sample. *Archives of Physical Medicine and Rehabilitation, 68*, 475-480.

Fuhrer, M. J., Rintala, D.H., Hart, K. A., Clearman, R., & Young, M. E. (1992). Relationship of life satisfaction to impairment, disability, and handicap among persons with spinal cord injury living in the community. *Archives of Physical Medicine and Rehabilitation, 73*, 552-557.

Glass, T. A., & Maddox, G. (1992). The quality and quantity of social support: Stroke recovery as psycho-social transition, *Social Science and Medicine, 34*(11), 1249-1261.

Goodenow, C., Resine, S. T., & Grady, K. E. (1990). Quality of social support and associated social and psychological functioning in women with rheumatoid arthritis. *Health Psychology, 9*, 266-284.

Goodinson, S. M., & Singleton, J. (1989). Quality of life: A critical review of current concepts, measures and their clinical implications. *International Journal of Nursing Studies, 26*(4), 327-341.

Granger, C. V., & Hamilton, B. B. (1993). The uniform data system for medical rehabilitation report of first admissions for 1991. *American Journal of Physical Medicine and Rehabilitation 72*(1), 33-38.

Grant, M., Padilla, G. V., Ferrell, B. R., & Rhiner, M. (1990). Assessment of quality of life with a single instrument. *Seminar in Oncology, 6*(4), 260-270.

Heart & Stroke Foundation of Canada. (1996, June). *Heart and stroke foundation surveys of Canadians.* Ottawa, ON: Author.

Holbrook, S. E. (1982). Stroke: Social and emotional outcome. *Journal of Royal College of Physicians of London, 16*, 100-104.

Holbrook, M., & Skilbeck, C.E. (1983). An Activities index for use with stroke patients. *Age and Ageing, 12*, 166-170.

House, A., Dennis, M., Mogridge, L., Warlow, C., Hawton, K., & Jones, L. (1991). Mood disorders in the first year after first stroke. *British Journal of Psychiatry, 153*, 83-90.

Jongbloed, L. & Crichton, A. (1990). A new definition of disability: Implications for rehabilitation practice and social policy. *Canadian Journal of Occupational Therapy, 57*(1), 32-37.

Kameyama, M., Udaka, F., Mezak, T., Sawada, H., Seriu, N., Shindo, K., & Nishitani, N. (1990). Quality of life after stroke. *Therapeutic Research, 8*(11), 26-32.

Kaun, Y. Y. (1990). *Subjective well-being of stroke survivors.* Unpublished doctoral dissertation, Vanderbilt University, TN.

Keith, R.A., Granger, C.V., & Hamilton, B.B., Sherwin, F. S. (1987). The functional independence measure: A new tool for rehabilitation. In M. G. Eisenberg, R.C. Grzesiak, (Eds.) *Advances in Clinical Rehabilitation* (pp. 6-18). New York, NY: Springer Publishing Co, Inc.

Kelly-Hayes, M., & Paige, C. (1995). Assessment and psychologic factors in stroke rehabilitation. *Neurology, 45* (suppl. 1), S29-S32.

King, R.B. (1990). *Quality of life after stroke.* Unpublished doctoral dissertation, University of Illinois, Chicago.

King, R. B. (1995). Quality of life after stroke. *Stroke, 27(9)*, 1467-1472.

Kinsella, G.J., & Duffey F. D. (1979). Psychological readjustment in the spouses of aphasic patients. *Scandinavian Journal of Rehabilitation Medicine, 11*, 129-132.

Labi, M.L.C., Phillips, T. F., & Gresham, G.E. (1980). Psychosocial disability in physically restored long-term stroke survivors. *Archives Physical Medicine Rehabilitation, 61,* 561-565.

Lalonde, M. (1975). A new perspective on the health of Canadians. Ottawa: Department of National Health & Welfare.

Law, M. (1991). 1991 Muriel Driver Lecture. The environment: A focus for occupational therapy. *Canadian Journal of Occupational Therapy, 58*(4), 171-179.

Letts, L., Fraser, B., Finlayson, M., & Walls, J. (1993). *For the health of it :Occupational therapy within a health promotion framework.* Toronto: CAOT Publications ACE.

Letts, L., Law, M., Rigby, P., Cooper, B., Stewart, D, & Strong, S. (1994). Person-environment assessments in occupational therapy. *The American Journal of Occupational Therapy, 48*(7), 608-618.

Lin, R.S., Simeone, W.M., Ensel, W.M., & Kuo, W. (1979). Social support, stressful life events, and illness: A model and empirical test. *Journal of Health and Social Behavior, 20,* 108-119.

MacLean, D. R. (1994). Theoretical rationale of community intervention for the prevention and control of cardiovascular disease. *Health Reports, 6*(1), 174-179.

Madill, H., Townsend, E., & Schultz, P. (1989). Implementing a health promotion strategy in occupational therapy education and practice. *Canadian Journal of Occupational Therapy,* 56(2), 67-72.

Mahoney, E. (1986). *The interaction of physical illness, coping focus, and perceived social support and their relationship to recovery from stroke.* Dissertation Abstract International, 47(5-B), 1929-1930. (University Microfilms No. 86-0081).

Marshak, L. E., & Seligman, M. (1993). *Counseling persons with physical disabilities.* Austin: Pro-Ed, Inc.

McColl, M. A., & Friedland, J. (1989). Development of a multidimensional index for assessing social support in rehabilitation. *The Occupational Therapy Journal of Research, 9* (4), 219-235.

McLeroy, K.R., DeVellis, R., Devellis, B., Kaplan, B., & Toole, J. (1984). Social support and physical recovery in a stroke population. *Journal of Social Personal Relationships, 1,* 395-413.

Morris, P. L., Robinson, R. G., Raphael, B., Bishop, D. (1991). The relationship between the perception of social support and post-stroke depression in hospitalized patients. *Psychiatry, 54*, 306-315.

Mossey, J., & Schapiro, E. (1982). Self-rated health: A predictor of mortality among the elderly. *American Journal of Public Health, 72*, 800-808.

Niemi, M., Laaksonen, R., Kotila, M, & Waltimo, O. (1988). Quality of life 4 years after stroke. *Stroke, 19*, 1101-1107.

Norland, J. (1994). *Profile of Canada's seniors: Focus on Canada.* Ottawa, ON: Statistics Canada & Prentice Hall Canada Inc.

Nydevik, I., & Hulter-Åsberg, K. (1992). Sickness Impact Profile: A three year follow-up. *Scandinavian Journal of Primary Health Care, 10*, 284-289.

Oleson, M. (1990). Subjectively perceived quality of life. *Journal of Nursing Scholarships, 22(3)*, 187-190.

Osberg, J. S., DeJong, G., Haley, S., Seward, M. L., McGinnis, M. P., & Germaine, J. (1988). Predicting long-term outcome among post-rehabilitation stroke patients. *American Journal of Physical Medicine and Rehabilitation, 67*, 94-103.

Padilla, G. V., Present, C., Grant, M. G., Metter, G., Lipsett, J., & Heide, F. (1983). Quality of Life Index for patients with cancer. *Research in Nursing and Health, 6*, 117-126.

Palmore, E., & Kivett, V. (1977). Change in life satisfaction: A longitudinal study of persons aged 46-70. *Journal of Gerontology, 32*, 311-316.

Pearlin, L. I. (1985). Social structure and processes of social support. In S. Cohen & L. Syme (Eds.), *Social Support and Health (pp. 43-60).* Orlando, FL: Academic Press.

Petrasovits, A., & Nair, C. (1994). Epidemiology of stroke in Canada. *Health Reports, 6*(1), 39-44.

Parikh, R., Lipsey, J., Robinson, R., & Price, T.R. (1987). A two-year longitudinal study of post-stroke mood disorders: Findings during the initial evaluation. *Stroke, 14*, 736-741.

Parikh, R., Robinson, R., Lipsey, J. (1990). The impact of post-stroke depression on recovery in activities of daily living over a 2-year follow-up. *Archives of Neurology, 47*, 785-789.

Polatajko, H. J. (1992). Muriel Driver Memorial Lecture. Naming and framing occupational therapy : A lecture dedicated to the life of Nancy B. *Canadian Journal of Occupational Therapy*, 59(4), 189-200.

Pollock, N. (1992). Client-centered assessment. *American Journal of Occupational Therapy, 47(4),* 298-301.

Popovich, J. M. (1992). Commentary on "poststroke family function: an evaluation of the family's role in rehabilitation." *Rehabilitation Nursing, 17*(3), 131-132.

Radloff, L.S., & Locke, B.Z. (1985). The community mental health assessment survey and the CES-D Scale. In M.M. Weissman, J.K. Myers, C.G.Ross (Eds.). *Community Surveys of Psychiatric Disorders*, New Brunswick, NJ: Rutgers University Press.

Renwick, R., Brown, I, & Nagler, M. (1996). *Quality of life in health promotion and rehabilitation: conceptual approaches, issues, and applications.* Thousands Oaks, CA: Sage Publications Inc.

Robertson, E. K., & Suinn, R. M. (1968). Determination of rate of progress of stroke patients through empathy measures of patient and family. *Journal of Psychosomatic Research, 12,* 189-191.

Robinson, R. G., Bolduc, P.L., & Price, T. R. (1987). Two-year longitudinal study of post-stroke mood disorders: Diagnosis and outcome of one to two years after stroke. *Stroke, 18*, 837-843.

Robinson, P.G., & Price, T.R. (1982). Post-stroke depressive disorders: follow-up study of 103 patients. *Stroke, 13*, 635-641.

Rootman, I., & Raeburn, I. (1994). The concept of health. In A. Pederson, M. O'Neill, & I. Rootman , (Eds.) *Health promotion in Canada* (pp. 56-71). Toronto: WB Saunders.

Sadin, K., Cif, D., & Noll, S. (1994). Stroke rehabilitation 4. Psychologic and social implications. *Archives of Physical Medicine and Rehabilitation, 75*, S52-S55.

Sauer, W.J., & Coward, R.T. (1985). *Social support networks and the care of the elderly.* New York, NY: Springer Publishing Company.

Santus, G., Ranzenigo, A., Caregnato, R., Inzoli, M. R. (1990). Social and family integration of hemispheric hemiplegic elderly patients 1 year after stroke. *Stroke, 21*, 1019-1022.

Shinar, D., Gross, C.R., Price, T.R., Banko, M., Bolduc, P.L. & Robinson, R.G. (1985). Screening for depression in stroke patients: The reliability and validity of the Center for Epidemiologic Studies Depression Scale. *Stroke, 17*(2), 241-245.

Schipper, H., Clinch, J., & Powell, V. (1990). Definitions and conceptual issues. In B. Spiler (Ed.), *Quality of Life assessments in clinical trials*, (pp. 11-23). New York, NY: Raven Press.

Schuling, J., de Haan, R., Limburg, M., & Groenier, K. H. (1993). The Frenchay Activities Index: Assessment of functional status in stroke patients. *Stroke, 24*,1173-1177.

Schulz, R., & Decker, S. (1985). Long-term adjustment to physical disability: The role of social support, perceived control, and self-blame. *Journal of Personality and Social Psychology, 48*, 1162-1172.

Segal, M. E., & Schall, R. R. (1994). Determining functional/health status and its relation to disability in stroke survivors. *Stroke, 25*(12), 2391-2397.

Short, S. (1981). An holistic approach towards disabled persons and their rehabilitation. *Australian Journal of Physiotherapy, 27*(5), 145-147.

Siler-Wells, H. (1988). *Directing change and changing direction : A new health policy agenda for Canada*. Ottawa : Canadian Public Health Association.

Sjogren K.(1982). Leisure after stroke. *International Rehabilitation Medicine, 4*, 80-87.

Smith, J. L. (1995). *Quality of life after traumatic brain injury.* Unpublished master dissertation. University of Alberta: Edmonton, AB.

Spilker, B. (1990). *Quality of life in clinical trials.* New York: Raven Press

SPSS (1994). *SPSS for windows release 6.1*, [computer software]. Copyright, June, 24, 1994, Chicago, IL: SPSS, Inc.

Stephens, M.A., Kinney, J. M., Norris, V. K.& Ritchie, S.W.(1987). Social networks as assets and liabilities in recovery from stroke by geriatric patients. *Psychology and aging, 2*, 125-129.

Stern, R., & Bachman, D. (1991) Depressive symptoms following stroke. *American Journal of Psychiatry, 148*, 351-356.

Stewart, M. J. (1995). Social support, coping, and self-care: Public participation concepts. In M. J. Stewart (Ed.), *Community nursing: Promoting Canadian's health* (pp. 89-124). Toronto, ON: W.B. Saunders.

Stroker, R. (1983). Impact of disability on family of stroke clients. *Journal of Neurosurgical Nursing, 15*, 360-363.

Thompson, S. C., Sobolew-Shubin, A., Graham, M. A., & Janigian, A. S. (1989). Psychosocial adjustment following a stroke. *Social Science and Medicine, 28*(3), 239-247.

Viitanen,M., Fugl-Meyer, K. S., Bernspång B., & Fugl-Meyer, A. R. (1988). Life satisfaction in long-term survivors after stroke. *Scandinavian Journal of Rehabilitation Medicine, 20,* 17-24.

Volicer, B. J. (1984). *Multivariate statistics for nursing research.* Orlando, FL: Grune & Stratton, Inc.

Whiteneck, G.G. (1994). The 44th John Stanley Coulter Lecture. Measuring what matters: Key rehabilitation outcomes. *Archives of Physical Medicine and Rehabilitation, 75,* 1073-1076.

Williams, A. (1993). Caregivers of persons with stroke: Their physical and emotional well-being. *Quality of Life Research, 2,* 213-219.

Widén-Holmqvist, L., Pedro-Cuesta, J, Holm, M.,Sandström, B., Hellblom, A., Stawiarz, L., & Bach-y-Rita, P. (1993). Stroke rehabilitation in Stockholm: Basis for late intervention in patients living at home. *Scandinavian Journal of Rehabilitation Medicine*, 25, 173-181.

Wood-Dauphinee, S. & Küchler, T. (1992). Quality of life as rehabilitation outcome: Are we missing the boat? *Canadian Journal of Rehabilitation, 6* (1), 3-12.

World Health Organization (1980). *International classification of impairments, disabilities and handicaps: A manual of classification relating to the consequences of disease (ICIDH).* Geneva, Switzerland: World Health Organization.

World Health Organization, Health and Welfare Canada & the Canadian Public Health Association. (1986). Ottawa charter on health promotion. *Canadian Journal of Public Health, 77,* 425-427.

APPENDIX A

INTRODUCTORY LETTER

Dear _____________,

The Glenrose Rehabilitation Hospital and the University of Alberta are studying the quality of life for persons after stroke. This information may help us to provide more appropriate stroke rehabilitation programs and to improve quality of life of patients with stroke. This letter is an invitation for you to participate in this study.

If you are in agreement, I will visit you in your home for 2.0 hours. First, I will interview you for about half an hour. Then you will be given seven short questionnaires. You will be asked questions about the activities you do and the kinds of supports you receive at home. You will also be asked questions regarding your feelings about health and life in general.

We will also need some personal information from you (e.g. date of birth, marital status). All information will be kept confidential. No information that identifies you will be included in any report on the study. Your participation is voluntary. You may withdraw from this study at any time, and this study will not affect any services you are receiving at this or future time.

You will be eligible for the study if you:

- have had a stroke as an adult between ages of 60 and 85 years.
- have only had one stroke.
- have been discharged from an inpatient rehabilitation program for at least 1 year, but not more than 3 years
- do not suffer from another major illness such as Multiple Sclerosis
- are able to comprehend verbal and written instructions
- are able to converse with little or no difficulty

_________ will be calling you in the next few days to ask if you are willing to participate in the study. A convenient meeting date will then be arranged if you are interested. If you have any further questions and do not wish to phone, please feel free to contact me at any time at (403) 439-9637.

Thank you for considering my request.

Sincerely,

Peter J. Kim	Margaret Hadley
Graduate Student	Nursing Unit Manager
Department of Occupational Therapy	Stroke/Brain Injury
Faculty of Rehabilitation Medicine	Glenrose Rehabilitation Hospital
The University of Alberta	

APPENDIX B

SAMPLE SIZE CALCULATION

Power test (after Cohen & Cohen, 1983)

$H_O: \quad R^2\langle \ .2$

$H_A:: \quad R^2\langle \ .2$

At an alpha level of .05 and a study power of .80, given thirteen variables, L=17.85

$$F^2 = \frac{R^2}{1-R^2}$$
$$= \frac{.2}{.8}$$
$$=.25$$

Where K equals the number of variables and $n^{\bullet}$ is the number of subjects required:

$$N^{\bullet} = \frac{L}{F^2} + k + 1$$
$$= \frac{17.85}{.25} + 13 + 1$$
$$= 85$$

Therefore, in order to find .2 variance at an alpha level of .05 with a study power of .80, approximately 85 subjects are needed.

APPENDIX C

NEUROLOGICAL STATUS FORM

Date of stroke __/__/__ (month, day, year)

First stroke? ___ 1. Yes ___ 2. No

Number of years since stroke ______

Date of discharge from rehabilitation ________

FIM score at discharge __________

Etiology
___ 1. Thrombosis
___ 2. Embolus
___ 3. Hemorrhage
___ 4. Undetermined

Side of lesion
___ 1. Right hemisphere
___ 2. Left hemisphere

Severity of Stroke (Motor, Perceptual & Sensory Deficits)____________________________
____
____

Comorbid Medical Conditions ______________________________________
____
____
____

APPENDIX D

CONSENT FORM

Title: Quality of life after stroke.

Principal Investigator:
Peter Kim, MSc. candidate, Rehabilitation Medicine,
University of Alberta. Tel. (403)439-9637

Co-investigators:
Margaret Hadley, Nursing Unit Manager, Stroke/Brain Injury
Glenrose Rehabilitation Hospital. Tel. (403)471-2262
Dr. Sharon A. Warren, Professor and Co-Supervisor, Faculty of
Rehabilitation Medicine, University of Alberta. Tel. (403)492-7856

Purpose: This study will look at factors that may affect your quality of life after stroke. You will be asked questions about the activities you do and the kinds of supports (family, friends) you have. You will also be asked questions regarding your feelings about health and life in general.

Procedures: You will be interviewed for about half an hour. Then you will be given seven questionnaires to complete. It will take about 2 hours total time. The researcher will help if you do not understand. All questionnaires will be administered in your home and completed during a maximum of two home visits.

Risk/Benefits: There are no known risks involved in participating in this study. The study has no direct benefit to participants. The researchers hope to learn about what affects quality of life after stroke. This may help us treat stroke patients more effectively in the future.

Confidentiality: Only the researchers will have access to information obtained from the interview/questionnaires. No names or other identifying information will be released. All information will be stored at a secure location.

Consent to be a Research Participant:

I understand that my participation is voluntary. I may refuse to answer any questions. I am free to withdraw my consent and stop my participation at any time without any consequences. This study will not affect any services that I am receiving at this time or any future time.

I understand that all information will be kept in complete confidence and will be accessible only to the researchers. I understand that researchers will be accessing my medical record from the Glenrose Rehabilitation Hospital to obtain information about my previous state of health.

I have read this form and talked with the researcher about this study. All of my questions about this study have been answered to my satisfaction. I am fully aware of what is involved in the study. At any time I will be free to ask any further questions about the study. I sign this consent form freely and will have received a copy of this form to keep for future reference.

APPENDIX D (Continued)

CONSENT FORM

If I have any further questions, I can contact Peter Kim at 439-9637. If I have concerns about how this research is being done, I can contact the Office of Research Services at the Glenrose Rehabilitation Hospital 471-2262 (ext. 2500).

Participant's signature Date

The person signing this form appears to understand what is involved in the study and voluntarily agrees to participate.

Researcher's signature Date

APPENDIX E

MINI-MENTAL STATE EXAMINATION

Maximum score	Score	
		Orientation
5	( )	What is the (year) (season) (date) (day) (month) ?
5	( )	Where are we:(state) (country) (town) (hospital) (floor).
		Registration
3	( )	Name 3 objects: 1 second to say each. Then ask the patient all 3 after you have said them. Give 1 point for each correct answer. Then repeat them until he learns all 3. Count trials and record. Trials:
		Attention and calculation
5	( )	Serial 7's. 1 point for each correct. Stop after 5 answers. Alternatively spell "world" backwards.
		Recall
3	( )	Ask for the 3 objects repeated above. Give 1 point for each correct.
		Language
9	( )	Name a pencil. and watch (2 point) Repeat the following "No ifs, ands or buts." (1 point) Follow a 3-stage command: "Take a paper in your right hand, fold it in half, and put it on the floor" (3 point) Read and obey the following: CLOSE YOUR EYES (1 point) Write a sentence (1 point) Copy design (1 point)

__________Total score

APPENDIX F

DEMOGRAPHIC DATA FORM

1.ID Number: _________

2.Age: ____ (Year)

3.Gender:
___ 1. Male
___ 2. Female

4.Marital Status:
___ 1. Married
___ 2. Widowed
___ 3. Separated
___ 4. Divorced
___ 5. Never Married

5.Education: Highest level of education completed (circle one)
___ 1. Master or doctoral degree
___ 2. College or university degree
___ 3. Some college training
___ 4. High school diploma
___ 5. Partial high school (grade 10-11)
___ 6. Junior high school (grade 7-9)
___ 7. Less than 7 years

6.Income:
___ 1. Less than $19,999 per year
___ 2. $20,000 to $39,999 per year
___ 3. $40,000 or more per year

7.Living arrangement:
___ 1. Alone
___ 2. With spouse
___ 3. Living with parents/ relatives
___ 4. With hired attendant
___ 5. With friend

8.Retirement: ___ 1. Yes ___ 2. No

9. Involvement in
Support Group: ___ 1. Yes ___ 2. No

APPENDIX G

SUBSCALES OF THE QUALITY OF LIFE INDEX (QLI): STROKE VERSION

Health and functioning subscale

1. own health
2. health care
3. pain
4. ability to do things for yourself
5. ability to get around
6. ability to go places outside home
7. ability to speak
9. long life
14. sex life
17. family responsibilities
18. usefulness to others
19. stress
27. leisure activities
28. travel
29. retirement

Socioeconomic subscale

15. friends
16. emotional support
20. home
21. neighborhood
22. standard of living
23./24. job/unemployment
25. education
26. financial independence

Psychological /spiritual subscale

30. peace of mind
31. faith in God
32. goals
33. happiness
34. life satisfaction
35. personal appearance
36. self

Family

10. family health
11. children
12. family happiness
13. spouse

APPENDIX G (continued)

THE QUALITY OF LIFE INDEX (Stroke/Head Injury Version)

Part I. For each of the following, please choose the answer that best describes how satisfied you are with that area of your life. Please mark your answer by circling the number. There are no right or wrong answers.

The numbed responses following the questions below relate to these response categories:

1 = Very Dissatisfied
2 = Moderately Dissatisfied
3 = Slightly Dissatisfied
4 = Slightly Satisfied
5 = Moderately Satisfied
6 = Very Satisfied

HOW SATISFIED ARE YOU WITH:

1. Your health ? 1 2 3 4 5 6

2. The health care you are receiving? 1 2 3 4 5 6

3. The amount of pain that you have? 1 2 3 4 5 6

4. Your ability to do things for yourself? 1 2 3 4 5 6

5. Your ability to get around (for example, walk or use or wheelchair)? 1 2 3 4 5 6

6. Your ability to go places outside your home? 1 2 3 4 5 6

7. Your ability to speak? 1 2 3 4 5 6

8. The amount of control you have over your life? 1 2 3 4 5 6

9. Your potential to live a long time? 1 2 3 4 5 6

10. Your family's health? 1 2 3 4 5 6

11. Your children? 1 2 3 4 5 6

APPENDIX G (continued)

1 = Very Dissatisfied
2 = Moderately Dissatisfied
3 = Slightly Dissatisfied
4 = Slightly Satisfied
5 = Moderately Satisfied
6 = Very Satisfied

HOW SATISFIED ARE YOU WITH:

---

12. Your family's happiness? 1 2 3 4 5 6

13. Your relationship with your spouse/ significant other? 1 2 3 4 5 6

14. Your sex life? 1 2 3 4 5 6

15. Your friends? 1 2 3 4 5 6

16. The emotional support you get from others? 1 2 3 4 5 6

17. Your ability to meet family responsibilities? 1 2 3 4 5 6

18. Your usefulness to others? 1 2 3 4 5 6

19. The amount of stress or worries in your life? 1 2 3 4 5 6

20. Your home? 1 2 3 4 5 6

21. Your neighborhood? 1 2 3 4 5 6

22. Your standard of living? 1 2 3 4 5 6

23. Your job (if employed)? 1 2 3 4 5 6

24. Not having a job (if unemployed retired or disabled)? 1 2 3 4 5 6

25. Your education? 1 2 3 4 5 6

APPENDIX G (continued)

1 = Very Dissatisfied
2 = Moderately Dissatisfied
3 = Slightly Dissatisfied
4 = Slightly Satisfied
5 = Moderately Satisfied
6 = Very Satisfied

HOW SATISFIED ARE YOU WITH:

---

26. Your financial independence?	1	2	3	4	5	6
27. Your leisure time activities?	1	2	3	4	5	6
28. Your ability to travel on vacations?	1	2	3	4	5	6
29. Your potential for a happy old/age retirement?	1	2	3	4	5	6
30. Your peace of mind?	1	2	3	4	5	6
31. Your personal faith in god?	1	2	3	4	5	6
32. Your achievement of personal goals?	1	2	3	4	5	6
33. Your happiness in general?	1	2	3	4	5	6
34. Your life in general?	1	2	3	4	5	6
35. Your personal appearance?	1	2	3	4	5	6
36. Yourself in general?	1	2	3	4	5	6

APPENDIX G (continued)

Part II. For each of the following, please choose the answer that best describes how important that area of your life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

The numbed responses following the questions below relate to these response categories:

1 = Very Unimportant
2 = Moderately Unimportant
3 = Slightly Unimportant
4 = Slightly Important
5 = Moderately Important
6 = Very Important

HOW IMPORTANT TO YOU IS:

---

1. Your health ? 1 2 3 4 5 6
2. The health care you are receiving? 1 2 3 4 5 6
3. Being completely free of pain? 1 2 3 4 5 6
4. To be able to do things for yourself? 1 2 3 4 5 6
5. To be able to get around (for example. walk or use or wheelchair)? 1 2 3 4 5 6
6. To go places outside your home? 1 2 3 4 5 6
7. To be able to speak? 1 2 3 4 5 6
8. Having control over your life? 1 2 3 4 5 6
9. Living a long time? 1 2 3 4 5 6
10. Your family's health? 1 2 3 4 5 6
11. Your children? 1 2 3 4 5 6
12. Your family's happiness? 1 2 3 4 5 6
13. Your relationship with your spouse/ significant other? 1 2 3 4 5 6

APPENDIX G (continued)

1 = Very Unimportant
2 = Moderately Unimportant
3 = Slightly Unimportant
4 = Slightly Important
5 = Moderately Important
6 = Very Important

HOW IMPORTANT TO YOU IS:

---

14. Your sex life? 1 2 3 4 5 6

15. Your friends? 1 2 3 4 5 6

16. Emotional support? 1 2 3 4 5 6

17. Meeting family responsibilities? 1 2 3 4 5 6

18. Being useful to others? 1 2 3 4 5 6

19. Having a reasonable amount of stress
or worries in your life? 1 2 3 4 5 6

20. Your home? 1 2 3 4 5 6

21. Your neighborhood? 1 2 3 4 5 6

22. A good standard of living? 1 2 3 4 5 6

23. Your job ? 1 2 3 4 5 6

24. To have a job? 1 2 3 4 5 6

25. Your education? 1 2 3 4 5 6

26. Your financial independence? 1 2 3 4 5 6

27. Leisure time activities? 1 2 3 4 5 6

APPENDIX G (continued)

1 = Very Unimportant
2 = Moderately Unimportant
3 = Slightly Unimportant
4 = Slightly Important
5 = Moderately Important
6 = Very Important

HOW IMPORTANT TO YOU IS:

---

28. The ability to travel on vacations?	1	2	3	4	5	6
29. Having a happy old/age retirement?	1	2	3	4	5	6
30. peace of mind?	1	2	3	4	5	6
31.Your personal faith in god?	1	2	3	4	5	6
32. Achieving personal goals?	1	2	3	4	5	6
33. Happiness?	1	2	3	4	5	6
34. Being satisfied with life?	1	2	3	4	5	6
35.Your personal appearance?	1	2	3	4	5	6
36. Are you to yourself?	1	2	3	4	5	6

APPENDIX H

FUNCTIONAL INDEPENDENCE MEASURE

Complete Independence: 7 (*Timely, Safely*)
Modified Independence: 6 (*Device*)
Modified Dependence: 5 *Supervision*
4 *Minimal Assist (Participant = 75% -)*
3 *Moderate Assist (Participant = 50% +)*
Complete Dependence: 2 *Maximal Assist (Participant = 25% -)*
1 *Total Assist (Participant = 0% -)*

Self-Care	ADMIT	DISCHG	FOL-UP
A. Eating	______	______	______
B. Grooming	______	______	______
C. Bathing	______	______	______
D. Dressing-Upper Body	______	______	______
E. Dressing- Lower Body	______	______	______
F. Toileting	______	______	______
Sphincter Control			
G. Bladder Management	______	______	______
H. Bowel Management	______	______	______
Transfers			
I. Bed, Chair, Wheelchair	______	______	______
J. Toilet	______	______	______
K.Tub, Shower	______	______	______
Locomotion L. Walk/Wheelchair	walk __ ______ w/c __ both __	walk __ ______ w/c __ both __	walk __ ______ w/c __ both __
M. Stairs	______	______	______
Motor Subtotal score	______	______	______
Communication			
N. Comprehension	___(Auditory/Visual/Both)	______(A/V/B)	______(A/V/B)
O. Expression	___(Vocal/Non-vocal/Both)	______(V/N/B)	______ (V/N/B)
Social Cognition			
P. Social Interaction	______	______	______
Q. Problem Solving	______	______	______
R. Memory	______	______	______
Cognitive Subtotal Score	______	______	______
Total FIM	______	______	______

APPENDIX I

FRENCHAY ACTIVITIES INDEX

During previous 3 months

Activity	Code
_ Preparing main meals _Washing-up	1= Never 2= Under once weekly 3= 1-2 times a week 4= Most days
_Washing clothes _Light housework _Heavy housework _Local shopping _Social outings _Walking outdoors over 15 min. _Pursuing active interest in hobby _Driving a car / travel on bus	1= Never 2= 1-2 times in 3 months 3= 3-12 times in 3 months 4= At least weekly

During previous 6 months

_Outings/ Car rides	1= Never 2= 1-2 times in 6 months 3= 3-12 times in 6 months 4= At least weekly
_ Gardening _ Household and / or car maintenance	1= None 2= Light 3= Moderate 4= All Necessary
_ Reading books	1= None 2= 1 in 6 months 3= Less than 1 a fortnight 4= Over 1 a fortnight
_Gainful work	1= None 2= Up to 10 h/week 3= 10-30 h/week 4= Over 30 h/week

Total___; Factor 1___; Factor 2____; Factor 3____.

APPENDIX J

THE SOCIAL SUPPORT INVENTORY FOR PEOPLE WITH ACQUIRED DISABILITY (SSIPAD)

1. Personal

First, let's talk about the person you said you feel closest to, your most important relationship.
(INTERVIEWER: remind of name or initial: _________)

What is your relationship with ________?
1 ( ) Mother
2 ( ) Father
3 ( ) Sister
4 ( ) Brother
5 ( ) Daughter
6 ( ) Son
7 ( ) Girlfriend
8 ( ) Boyfriend
9 ( ) Friend
10 ( ) Other

Did you know ______ before your illness/injury? 1 ( ) Yes
2 ( ) No

Do you live with _______ ? 1 ( ) Yes
2 ( ) No

Does ________have a disability ? 1 ( ) Yes /Specify:
2 ( ) No

About how often do you see ______?
1 ( ) every day
2 ( ) couple of times a week
3 ( ) once a week
4 ( ) less than once a week

About how much time do you usually spend with ______ on each of these occasions?
1 ( ) all day
2 ( ) half day
3 ( ) couple of hours
4 ( ) less than two hours

What kind of support does _______give you?

APPENDIX J (continued)

THE SOCIAL SUPPORT INVENTORY FOR PEOPLE WITH ACQUIRED DISABILITY (SSIPAD)

How happy are you with the amount of time you spend with _______ ?

5 ( ) very happy
4 ( ) quite happy
3 ( ) fairly happy
2 ( ) not that happy
1 ( ) not happy at all

How happy are you with the way you and _______ get along together at the present?

5 ( ) very happy
4 ( ) quite happy
3 ( ) fairly happy
2 ( ) not that happy
1 ( ) not happy at all

How much can you count on _______ to be there when you need him or her?

5 ( ) very dependable
4 ( ) quite dependable
3 ( ) fairly dependable
2 ( ) not that dependable
1 ( ) not dependable at all

How close do you feel to _______ at present?

5 ( ) very close
4 ( ) quite close
3 ( ) fairly close
4 ( ) not that close
5 ( ) not close at all

Do you and _______ generally do things for one another, or would you consider your relationship with _____ one-sided in any way?

5 ( ) very one-sided in his/her favor
4 ( ) somewhat one-sided in his/her favor
3 ( ) pretty much equal
2 ( ) somewhat one-sided in my favor
1 ( ) very one-sided in my favor

How has your relationship with _______ changed since your illness?

APPENDIX J (continued)

THE SOCIAL SUPPORT INVENTORY FOR PEOPLE WITH ACQUIRED DISABILITY (SSIPAD)

2. Family and Close Friends

When we talked about family and close friends earlier, you mentioned several people
(INTERVIEWER: Remind of names or initials)

Please CHOOSE ONE about whom to answer the following questions.
(INTERVIEWER: Note choice:____________________)

What is your relationship with the person you have chosen _________?
1 ( ) Mother
2 ( ) Father
3 ( ) Sister
4 ( ) Brother
5 ( ) Daughter
6 ( ) Son
7 ( ) Girlfriend
8 ( ) Boyfriend
9 ( ) Friend
10 ( ) Other

Did you know ______ before your illness/injury? 1 ( ) Yes
2 ( ) No

Do you live with _______ ? 1 ( ) Yes
2 ( ) No

Does ________have a disability ? 1 ( ) Yes /Specify:
2 ( ) No

About how often do you see ______? 1 ( ) every day
2 ( ) couple of times a week
3 ( ) once a week
4 ( ) less than once a week

About how much time do you usually spend with ______ on each of these occasions?
1 ( ) all day
2 ( ) half day
3 ( ) couple of hours
4 ( ) less than two hours

What kind of support does _______give you?

APPENDIX J (continued)

THE SOCIAL SUPPORT INVENTORY FOR PEOPLE WITH ACQUIRED DISABILITY (SSIPAD)

How happy are you with the amount of time you spend with _______ ?

5 ( ) very happy
4 ( ) quite happy
3 ( ) fairly happy
2 ( ) not that happy
1 ( ) not happy at all

How happy are you with the way you and _______ get along together at the present?

5 ( ) very happy
4 ( ) quite happy
3 ( ) fairly happy
2 ( ) not that happy
1 ( ) not happy at all

How much can you count on _______ to be there when you need him or her?

5 ( ) very dependable
4 ( ) quite dependable
3 ( ) fairly dependable
2 ( ) not that dependable
1 ( ) not dependable at all

How close do you feel to _______ at present?

5 ( ) very close
4 ( ) quite close
3 ( ) fairly close
4 ( ) not that close
5 ( ) not close at all

Do you and ________ generally do things for one another, or would you consider your relationship with _____ one-sided in any way?

5 ( ) very one-sided in his/her favor
4 ( ) somewhat one-sided in his/her favor
3 ( ) pretty much equal
2 ( ) somewhat one-sided in my favor
1 ( ) very one-sided in my favor

How has your relationship with ________ changed since your illness?

APPENDIX J (continued)

THE SOCIAL SUPPORT INVENTORY FOR PEOPLE WITH ACQUIRED DISABILITY (SSIPAD)

3. Community Individuals

We also talked about the individuals in your community with whom you are in regular contact, such as:_________ (Interviewer: Remind)

Please CHOOSE ONE of these people about whom to answer the remaining questions.

What is your relationship with ________?

1 ( ) Mother
2 ( ) Father
3 ( ) Sister
4 ( ) Brother
5 ( ) Daughter
6 ( ) Son
7 ( ) Girlfriend
8 ( ) Boyfriend
9 ( ) Friend
10 ( ) Other

Did you know ______ before your illness/injury?
1 ( ) Yes
2 ( ) No

Does ________have a disability ?
1 ( ) Yes /Specify:
2 ( ) No

About how often do you see ______?
1 ( ) every day
2 ( ) once or twice a week
3 ( ) two or three times a month
4 ( ) less than once a month

About how much time do you usually spend with ______ on each of these occasions?
1 ( ) half day or more
2 ( ) one or two hours
3 ( ) about half an hour
4 ( ) a few minutes

What kind of support does _______give you?

APPENDIX J (continued)

THE SOCIAL SUPPORT INVENTORY FOR PEOPLE WITH ACQUIRED DISABILITY (SSIPAD)

How happy are you with the amount of time you spend with _______ ?

5 ( ) very happy
4 ( ) quite happy
3 ( ) fairly happy
2 ( ) not that happy
1 ( ) not happy at all

How happy are you with the way you and _______ get along together at the present?

5 ( ) very happy
4 ( ) quite happy
3 ( ) fairly happy
2 ( ) not that happy
1 ( ) not happy at all

How much can you count on _______ to be there when you need him or her?

5 ( ) very dependable
4 ( ) quite dependable
3 ( ) fairly dependable
2 ( ) not that dependable
1 ( ) not dependable at all

How close do you feel to _______ at present?

5 ( ) very close
4 ( ) quite close
3 ( ) fairly close
4 ( ) not that close
5 ( ) not close at all

Do you and _______ generally do things for one another, or would you consider your relationship with _____ one-sided in any way?

5 ( ) very one-sided in his/her favor
4 ( ) somewhat one-sided in his/her favor
3 ( ) pretty much equal
2 ( ) somewhat one-sided in my favor
1 ( ) very one-sided in my favor

How has your relationship with _______ changed since your illness?

APPENDIX J (continued)

THE SOCIAL SUPPORT INVENTORY FOR PEOPLE WITH ACQUIRED DISABILITY (SSIPAD)

4. Community Groups

You mentioned several groups that you belong to earlier: (INTERVIEWER: remind ________)

Please CHOOSE ONE about which to answer the following questions.
(INTERVIEWER: note choice:____________)

Did you belong to this group before your illness/injury? 1 ( ) Yes
2 ( ) No

Is this group for people with disability ? 1 ( ) Yes
2 ( ) No

About how often do you meet this group?
1 ( ) more than once a week
2 ( ) once a week
3 ( ) once or twice a month
4 ( ) less than once a month

About how much time do you usually spend with this group on each occasion?
1 ( ) half day or more
2 ( )several hours
3 ( ) one hour
4 ( ) less than an hour or less

What kind of support does ______give you?

APPENDIX J (continued)

THE SOCIAL SUPPORT INVENTORY FOR PEOPLE WITH ACQUIRED DISABILITY (SSIPAD)

How happy are you with the amount of time you spend with <u>this group</u> ?

5 ( ) very happy
4 ( ) quite happy
3 ( ) fairly happy
2 ( ) not that happy
1 ( ) not happy at all

How happy are you with the way you get along in this group at the present?

5 ( ) very happy
4 ( ) quite happy
3 ( ) fairly happy
2 ( ) not that happy
1 ( ) not happy at all

How much can you count on this group to respond to your issues?

5 ( ) very dependable
4 ( ) quite dependable
3 ( ) fairly dependable
2 ( ) not that dependable
1 ( ) not dependable at all

How close do you feel a part of this group at present?

5 ( ) very much a part
4 ( ) quite a part
3 ( ) fairly much a part
4 ( ) not that much a part
5 ( ) not at all a part

Do you feel you benefit more from the group, that they benefit from having you there, or that it is about equal?

5 ( ) very one-sided in group's favor
4 ( ) somewhat one-sided in group's favor
3 ( ) pretty much equal
2 ( ) somewhat one-sided in my favor
1 ( ) very one-sided in my favor

How has your relationship with this group changed since your illness/illness?

APPENDIX J (continued)

THE SOCIAL SUPPORT INVENTORY FOR PEOPLE WITH ACQUIRED DISABILITY (SSIPAD)

5. Professionals

Referring now to professionals who you mentioned earlier: (INTERVIEWER: remind_________)

Please CHOOSE ONE about whom to answer the following questions.
(INTERVIEWER: note choice: ___________)

Did you know ______ before your illness/injury? 1 ( ) Yes
2 ( ) No

Does _______have a disability ? 1 ( ) Yes /Specify:
2 ( ) No

About how often do you see _____? 1 ( ) more than once a week
2 ( ) once or twice a month
3 ( ) every couple of months
4 ( ) once or twice a year

About how much time do you usually spend with ______ on each visit?
1 ( ) couple of hours or more
2 ( ) about an hour
3 ( ) about half an hour
4 ( ) a few minutes

What kind of support does ______give you?

APPENDIX J (continued)

THE SOCIAL SUPPORT INVENTORY FOR PEOPLE WITH ACQUIRED DISABILITY (SSIPAD)

How happy are you with the amount of time you spend with _______ ?

5 ( ) very happy
4 ( ) quite happy
3 ( ) fairly happy
2 ( ) not that happy
1 ( ) not happy at all

How happy are you with the kind of relationship you have with _______ at the present?

5 ( ) very happy
4 ( ) quite happy
3 ( ) fairly happy
2 ( ) not that happy
1 ( ) not happy at all

How dependable you feel _______ would be if needed him or her?

5 ( ) very dependable
4 ( ) quite dependable
3 ( ) fairly dependable
2 ( ) not that dependable
1 ( ) not dependable at all

In general, how comfortable do you feel with _______ at present?

5 ( ) very comfortable
4 ( ) quite comfortable
3 ( ) fairly comfortable
4 ( ) not that comfortable
5 ( ) not comfortable at all

How has your relationship with _______ changed since your illness/injury?

APPENDIX K

PERCEIVED HEALTH STATUS

Compared to other persons your age, how would you rate your overall health?

5. Excellent (never prevents activities)
4. Good (rarely prevents activities)
3. Fair (occasionally prevents activities)
2. Poor (very often prevents activities)
1. Very Poor (health troubles or infirmity all the time prevents most activities-requires confinement to bed)

APPENDIX L

THE CES-D SCALE

Circle the number for each statement which best describes how often you felt or behaved this way- During THE PAST WEEK.

Depression Scale

0 Rarely or none of the time (less than 1 day)
1 Some or little of the time (1-2 days)
2 Occasionally or a moderate amount of time (3-4 days)
3 Most or all of the time (5-7 days)

During the past week:	**Less than 1 day**	**1-2 days**	**3-4 days**	**5-7 days**
1. I was bothered by things that usually don't bother me.	0	1	2	3
2. I did not feel like eating; my appetite was poor.	0	1	2	3
3. I felt that I could not shake off the blues even with help from my family or friends.	0	1	2	3
4. I felt that I was just good as other people.	0	1	2	3
5. I had trouble keeping my minds on what I was doing.	0	1	2	3
6. I felt depressed (blue or down).	0	1	2	3
7. I felt that everything I did was an effort.	0	1	2	3
8. I felt hopeful about future.	0	1	2	3
9. I thought my life had been a failure.	0	1	2	3
10. I felt fearful.	0	1	2	3
11. My sleep was restless.	0	1	2	3
12. I was happy.	0	1	2	3
13. I talked less than usual.	0	1	2	3
14. I felt lonely.	0	1	2	3
15. People were unfriendly.	0	1	2	3
16. I enjoyed life.	0	1	2	3
17. I had crying spells.	0	1	2	3
18. I felt sad.	0	1	2	3
19. I felt that people disliked me.	0	1	2	3
20. I could not get "going"	0	1	2	3

CES-D Score

Items 4, 8, 12, and 16 have their values reversed before totaling.

Source: Shinar, D., Gross, C.R., Price, T.R., Banko, M., Bolduc, P.L., & Robinson, R.G. (1985). Screening for depression in stroke patients: The reliability and validity of the Center for Epidemiologic Studies Depression Scale. *Stroke*, *17*(2), 241-245.

APPENDIX M

SUMMARY OF THE SCORING PROCEDURE FOR THE QUALITY OF LIFE INDEX

STEP	CALCULATION
1. Recode satisfaction scores.	To center the scale on zero, subtract 3.5 from the satisfaction response for each item.
2. Adjust item scores.	To obtain adjusted item scores, multiply the recoded satisfaction score by the importance score, item by item.
3. Obtain sum from overall adjusted score.	Sum all adjusted item scores.
4. Obtain sum for health and functioning subscale.	Sum the adjusted scores for the individual items of the health and functioning subscale.
5. Obtain sum for socioeconomic subscale.	Sum the adjusted scores for the individual items of the socioeconomic subscale.
6. Obtain sum for psychological/spiritual subscale.	Sum the adjusted scores for the individual items of the psychological/spiritual subscale.
7. Obtain sum for family subscale	Sum the adjusted scores for the individual items of the family subscale.
8. Obtain final overall score and subscale scores.	To prevent bias due to missing scores, divide each sum of items obtained in steps 3 through 7 by the number of items answered. To eliminate negative values, add 15 to every score to get the final score.