# QUALITY OF LIFE OF STROKE SURVIVORS WHO ATTEND A STROKE CLUB AND THEIR PERSONAL CAREGIVERS

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#### ABSTRACT

Stroke survivors are increasing in numbers and being discharged home sooner, often to the care of an informal personal caregiver. Little is known about the quality of life of community-dwelling stroke survivors who attend a stroke support group and their personal unpaid caregivers in British Columbia. Quantitative questionnaires were used to examine stroke survivor function, caregiver burden, health and quality of life.

The B.C stroke survivors' level of function was skewed towards the independent end of the Frail Elderly Functional Assessment (FEFA) scale. Self-reported health was worse on at least 7 of the 8 SF-36 subscales for stroke survivors compared to seven comparison groups, one with similar demographics. Some correlations among mean scores for stroke survivor FEFA and other stroke survivor variables were statistically significant; FEFA with three SF-36 subscales (physical functioning, general health and social function), with one satisfaction dimension (health), and with one quality of life measure (satisfaction with overall quality of life). All correlations among mean scores for each of the three measures of quality of life and 11 dimensions of satisfaction were statistically significant; however, the pattern of response was like the ordinary population on only one correlation. In summary, B.C. stroke survivors: had poor health; were independent in function; function was only somewhat related to their health, satisfaction or quality of life; and used different satisfaction domains from the general population on two of the three measures of quality of life.

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The B.C caregivers' level of burden was higher on the Caregiver Burden Scale (CBS) than one comparison group of caregivers. The caregivers had similar self-reported health status when compared to two Australian caregivers of stroke survivor studies and had worse self-reported health status on at least 7 of 8 SF-36 scales when compared to a minor medical illness group and the general population. All correlations among mean scores for CBS and caregiver variables were statistically significant; CBS with 8 SF-36 subscales, with 11 domain satisfaction subscales, and with 3 quality of life measures. Some correlations among mean scores for CBS and stroke survivor variables were statistically significant; CBS with stroke survivor FEFA, with stroke survivor SF-36 bodily pain, and with stroke survivor SF-36 general health. All correlations among mean scores for each of the three measures of quality of life and 11 dimensions of satisfaction were statistically significant. However, caregivers' pattern of response was like the general population on only two correlations. In summary, B.C. caregivers: had similar self-reported health to other caregiver groups but was wor; than the general population; experienced burden related to their health, domain satis faction, and quality of life; their burden was related to stroke survivor function; and used different satisfaction domains from the general population on one of the three measures of quality of life.

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#### **CHAPTER I**

#### **RESEARCH PROBLEM & LITERATURE REVIEW**

"Those in rehabilitation medicine have a history to be proud of: following our intuition based upon professional experience and altruistic instincts, we have always valued quality of life, encouraging our patients to strive for the highest goals to which they aspired, and providing the technical assistance needed to make those aspirations a reality ... but given all the challenges today 'Are we in danger of losing our way?'" deLateur, 1997

## Introduction

Stroke can be defined as 'rapidly developing clinical signs of focal or global disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin' (WHO MONICA Project, Bonita, 1992, p. 342). The absolute numbers of stroke survivors will rise significantly as the age of the population increases (Bonita, 1992). In Canada, stroke care accounts for the second highest number of person-days of hospitalization in Canada (Smurawska, Alexandrov, Bladin & Norris, 1994), is the third leading cause of death, and the leading cause of loss of function in adults (Shannon, Buller-Taylor, Milligan, Vossen & Frankish, 1997). Stroke rehabilitation is a restorative learning process that maximizes recovery by treating disabilities and preparing the stroke survivor to reintegrate as fully as possible into community life (U.S. Department of Health and Human Services, 1995). However, physical and functional restoration in isolation from the context of a person's psychosocial environment are insufficient to improve quality of life following disability (Kim, Warren, Madill & Hadley, 1999).

The majority of community-dwelling stroke survivors are supported by a personal unpaid caregiver. Many caregivers experience burden due to the devastating effects of stroke on their partner and themselves (Scholte op Reimer, de Haan, Rijnders, Limburg & van den Bos, 1998). The relationships between stroke survivors and caregivers, and among function, health and quality of life are complex. For example, while some studies suggest that patient factors affect caregiver health, well-being, or both; other studies suggest that family problems affect stroke survivor rehabilitation negatively (Bugge, Alexander & Hagen, 1990). Hop, Rinkel, Algra and van Gijin (1998) found that stroke survivors with no handicap had no reduction in quality of life while all other stroke survivors, including those with minor handicap, had reduced quality of life. As well, they found that caregiver quality of life was inversely related to stroke survivor handicap.

#### Statement of the Problem

Little is known about the quality of life of community-dwelling stroke survivors who attend a stroke support group and their personal unpaid caregivers in British Columbia. To learn more, the first objective of this study was to describe these stroke survivors and caregivers using quality of life and other variables. The second objective was to compare descriptive results to the literature and to examine relationships among the variables. The third objective was to examine variables that best explain stroke survivor quality of life and caregiver quality of life.

## **Definition of Terms**

The central terms used in this study were defined as follows:

1. A <u>stroke survivor</u> was defined as a person who has had a stroke<sup>1</sup>, is community-dwelling (not institutionalized), and attends a Stroke Recovery Association of British Columbia

<sup>&</sup>lt;sup>1</sup> If the person has had a stroke, has been told he/she has had a stroke or believes he/she has had a stroke then the person has had a stroke; no diagnostic testing of stroke was conducted.

(SRABC) stroke club. Stroke survivors who met these criteria can be assumed to have improved function compared to institutionalized stroke survivors.

- 2. A <u>caregiver</u> was defined as the person who helps the stroke survivor in everyday living but is not paid to do so. Caregivers are sometimes called personal, informal, unpaid or family caregivers. The caregiver is the person most closely involved in maintaining the stroke survivor's ability to live at home (Anderson, Linto & Stewart-Wynne, 1995) or the person who helps the stroke survivor the most but is not paid to do so (Bugge, Alexander & Hagen, 1999).
- <u>A stroke survivor-caregiver dyad</u> was defined as a matched stroke survivor-caregiver pair. Matching was demonstrated by questionnaires with matching numbers and congruent demographic answers.
- Quality of life was defined and operationalized as satisfaction with life as a whole, satisfaction with overall quality of life, and happiness with life as a whole. Each was measured on a 7-point scale (Michalos, Zumbo & Hubley, 2000).
- <u>Function</u> was defined as the ability to carry out functional activities that affect caregiver burden. Stroke survivor function was measured with the Frail Elderly Functional Assessment (Gloth, Scheve, Shah, Ashton & McKinney, 1999).
- <u>Caregiver burden</u> was defined as subjective impact of caregiving on well-being and health. Caregiver burden was measured with the Caregiver Burden Scale (Elmstahl, Malmberg & Annerstedt, 1996).
- Health was defined as perceived health status. Self-reported health status was measured with the SF-36 (McCallum, 1995).

 <u>Domain satisfaction</u> was defined as satisfaction with 12 domains of life. Each domain was measured on a 7-point scale (Michalos, Zumbo & Hubley, 2000).

## **Stroke Survivors**

## **Stroke Statistics**

The incidence of stroke in Canada is uncertain but is known to increase with age (Shannon, Buller-Taylor, Milligan, Vossen & Frankish, 1997). In New Zealand the incidence of stroke in ages 65-74, 75-84 and over 85 years is approximately 80, 100 and 180 per 10,000 respectively (Bonita, 1992). Approximately 50,000 Canadians will have a stroke each year; of these, 25% will die, making stroke the third leading cause of death (Shannon et al., 1997). Equal numbers of Canadian men and women will have a stroke. However, Canadian women who have a stroke are significantly older than men (77+/-12 years for women, and 73+/-11 years for men) and are twice as likely to die (34% for women, and 17% for men) (Smurawska, Alexandrov, Bladin & Norris, 1994). Age-standardized mortality rates for stroke in Canada are 49/100,000 for men and 42/100,000 for women, with similar rates in British Columbia (Shannon et al., 1997). Although studies in the USA show that the mortality rate is decreasing for stroke (Shahar, McGovern, Sprafka, Pankow, Doliszny, Luepker & Blackburn, 1995), stroke survivors have greater mortality compared to age- and gender-matched controls (Gresham, Kelly-Hayes, Wold, Beiser, Kase & E'Agostino, 1998). The prevalence of stroke in Canada for people over 65 years is 9%, which is a rough indicator of society burden or resource needs (Shannon et al., 1997). With increased incidence and decreased mortality, the absolute numbers of stroke victims will rise significantly as the age of the population increases (Bonita, 1992).

## **Cost of Stroke Care**

In Canada, stroke care accounts for the second largest number of person-days of hospitalization. A study at a teaching hospital in Toronto, Ontario in 1991-2 found no significant difference for length of stay between types of stroke but did find a significant difference for gender. Women had longer lengths of stay than men. More men than women went home or to rehabilitation; more women than men went to long-term care facilities. The average cost of acute care was \$27,500 per stroke victim (Smurawska, Alexandrov, Bladin & Norris, 1994). Disability payments for stroke amount to more than \$100 million annually in Canada. The total cost of stroke was estimated to be \$2.5 billion in Canada in 1986 (Shannon, Buller-Taylor, Milligan, Vossen & Frankish, 1997).

#### **Effects of Stroke**

Some of the many effects of stroke include hemiplegia, cognitive deficits, communication disorders, psychosocial problems (depression, anxiety, emotional instability, feeling of loss of control, fears about death and disfigurement, social isolation, helplessness, worry about loss of social roles) and changes in family unit (financial strain, emotional strain, changes in family roles) (Shannon, Buller-Taylor, Milligan, Vossen & Frankish, 1997). Jorgensen, Reith, Nakayama, Kammersgaard, Raaschou and Olsen (1999) found that independent predictors of good functional outcome following stroke were decreasing age, a spouse, lower body temperature on hospital admission, and neurological recovery. Jongbloed and Jones (1988) found function or stroke severity at admission predicted functional recovery at 4 and 8 weeks. Stineman, Maislin, Fiedler and Granger (1997) found that a greater improvement in function from the acute phase to rehabilitation corresponded with a greater likelihood of being discharged

home. Alexander (1994) found that the predictors for being discharged home for all stroke survivors, were younger age (less than 55 years) and less severe stroke.

The effect of post-stroke depression (PSD) is common (prevalence is between 25-75%), is difficult to assess (psychological tests may not be valid on neurologically impaired patients), and is undertreated (Gordon & Hibbard, 1997). In a Canadian study, Bacher, Korner-Bitensky, Mayo, Becker and Coopersmith (1990) found more than half of the stroke survivors were clinically depressed 12 months post-stroke and recommended that treatment for depression be incorporated into the rehabilitation program. Ten years later, Canadian researchers Singh, Black, Herrmann, Leibovitch, Ebert, Lawrence and Szalai (2000) found 36% of stroke survivors were depressed at 3 months post-stroke, and that low function at 1 month was predictive of low function and depression at 3 months. The probability of developing PSD is associated with being female, having more than 8 years of schooling (Paolucci, Antonucci, Pratesi, Traballesi, Grasso & Lubich, 1999), being female, previous depression, neurological impairments (Herrmann, Black, Laurence, Szekely & Szalai, 1998), residual functional limitations (Singh, Black, Herrmann, Leibovitch, Ebert, Lawrence & Szalai, 2000), and severe prognostic score at outset of stroke (Kotila, Numminen, Waltimo & Kaste, 1998). There was no association with age, lesion volume, side of lesion (Herrmann et al., 1998), or lesion site (Paolucci et al., 1999).

The effects of stroke change over time, as illustrated by studies done 5, 14 and 20 years poststroke. A study in England looked at the effects of stroke 5 years post-stroke. The original group consisted of 291 stroke survivors in 1989/90. Standardized tests carried out 5 years later with 109 participants (of 123 survivors) found 66% were disabled, 36% were depressed or

borderline depressed, and 47% had an identified caregiver (Wilkinson, Wolfe, Warburton, Rudd, Howard, Ross-Russell & Beech 1997). A study in Finland looked at the effects of stroke 14 years post-stroke. The original group included 1,241 stroke survivors in 1972-1974. Researcher-developed assessments carried out 14 years later with 201 participants (of 241 survivors) found 85% could mobilize independently, 86% could pursue recreation/leisure activities, 58% had paralysis of a leg or arm, 34% were unable to cope with household management, 39% were unable to cope with self-care, 53% reported low mood or were depressed, and 14% reported poor health (Tuomilehto, Nuottimaki, Salmi, Aho, Kotila, Sarti & Rastenyte, 1995). The Framingham study in the USA looked at the effects of stroke 20 years post-stroke. The original group included 155 stroke survivors in 1972-1975. Standardized tests carried out 20 years later with 9 participants (of 10 survivors) found that 8/9 scored normal on cognitive tests, had no depressive symptoms, mobilized independently with or without mobility aids, and were independent for activities of daily living (ADL) with or without assistive devices (Gresham, Kelly-Hayes, Wolf, Beiser, Kase & D'Agostino, 1998).

## Rehabilitation

#### **Rehabilitation Framework**

In 1965, Nagi developed the Functional Limitation Model which defined pathology, impairment, functional limitation and disability, examined the causative role of risk factors, and emphasized the importance of quality of life. In 1980, the World Health Organization (WHO) developed the Disablement Model characterized by the International Classification of Impairment, Disability and Handicap (ICIDH). Today, concepts from the two models are combined to form a rehabilitation framework (U.S. Department of Health and Human Services, 1995). The

rehabilitation framework illustrates and defines rehabilitation conditions, key terms, analysis and intervention at the organ-level, person-level, and societal-level (see Appendix A).

The key term, impairment, refers to loss or abnormality of physical or psychological capacities at the organ-level. Examples include loss or abnormality of anatomy, physiology, mental capacity or physical structures. According to the rehabilitation framework, the underlying condition would be pathology, analysis would be diagnostic, and intervention would be medical or restorative rehabilitation (see Appendix A). Impairment may be measured globally, for example, the Canadian Neurological Scale, or singularly such as motor skills, balance, cognition or depression (Mayo, Wood-Dauphinee, Cote, Gayton, Carlton, Buttery & Tamblyn, 2000).

The key term, disability, refers to a restriction or lack of ability to perform an activity of daily living (ADL). Basic ADLs include grooming, hygiene, dressing, bathing and toileting; and instrumental ADLs include banking, shopping, and household management. According to the rehabilitation framework, the underlying condition would be behavioral. Rehabilitation analysis would be performance or behavioral evaluation. Rehabilitation intervention would involve using adaptive equipment, improving the physical environment, or reducing attitudinal barriers (see Appendix A). Some common ADL measures include the Barthol Index (BI), Functional Independence Measure (FIM), Frenchay Activity Index, Older Americans Resource Scale for IADL (OAR-IADL) and Katz ADL (Mayo, Wood-Dauphinee, Cote, Gayton, Carlton, Buttery & Tamblyn, 2000; Pederson, Jorgensen, Nakayama, Raaschou & Olsen, 1997; Spector, 1996; Stinemann, Jette, Fiedler & Granger, 1997). The Frail Elderly Functional Assessment (FEFA) includes ADL items that are relevant to frail elders living in the community and that have an

impact on their caregivers (Gloth, Walston, Meyer & Pearson, 1995). For this research, the FEFA was selected to be the measure for stroke survivor function.

The key term, handicap, refers to a disadvantage which results from an impairment or disability that limits or prevents fulfillment of a social role and encompasses both environmental and societal deficits/norms/policy. According to the rehabilitation framework, the underlying condition would be an interruption in roles due to environment or social deficits. Rehabilitation analysis would be through role descriptors. Rehabilitation intervention would be through supportive services and social policy changes (see Appendix A). Two measures of handicap include the Rankin Scale (U.S. Department of Health and Human Services, 1995) and the Return to Normal Living (RNL) Index (Mayo, Wood-Dauphinee, Cote, Gayton, Carlton, Buttery & Tamblyn, 2000).

Although the rehabilitation framework helps to explain rehabilitation concepts, there are limitations. The terms impairment, disability and handicap, are well defined in the rehabilitation framework, but often and incorrectly the terms are used interchangeably. Tools that measure impairment, disability or handicap are often not sufficiently discrete. For example, the Rankin Scale, which was designed to measures handicap, also measures impairment and disability (De Haan, Limburg, Bossuyt, van der Meulen & Aaronson, 1995). Another aspect of the rehabilitation framework that is problematic is that it depicts a causal relationship among these terms, whereby impairment leads to disability and disability leads to handicap. However, Roth, Heinemann, Lovell, Harvey, McGuire and Diaz (1998) showed that level of impairment only partially explained the level of disability during stroke rehabilitation.

## **Stroke Rehabilitation Programs**

Comprehensive stroke rehabilitation is described as a multidimensional process consisting of prevention and treatment of medical complications, restoration of maximal independent functioning, facilitation of psychosocial coping and adaptation by the patient and family, promotion of community reintegration, and enhancing quality of life of stroke survivors (Roth, Heinemann, Lovell, Harvey, McGuire & Diaz, 1998). Measuring outcomes of stroke rehabilitation is complex but most of the research indicates that stroke rehabilitation is effective.

Cifu and Stewart (1999) reviewed stroke rehabilitation literature published from 1950-1998 and found that functional outcome has improved over time. Improved functional outcomes were observed with reduced acute inpatient hospital time and early rehabilitation services (Mayo, Hendlisz & Korner-Bitensky, 1989), treating stroke patients on a neurology, rehabilitation or stroke unit instead of a general medical ward (Jorgensen, Nakayama, Raaschou, Larsen, Hubbe & Olsen, 1995; Kalra, 1994; Kaste, Palomaki & Sarna, 1995), and using a coordinated multidisciplinary stroke team instead of general medical care on a general unit (Webb, Fayad, Wilbur, Thomas & Brass, 1995). In Hong Kong, Hui, Lum, Woo and Kay (1995) found stroke patients discharged early with day hospital rehabilitation had better function than patients treated on a neurological unit. In a randomized control trial (RCT) in the USA, Holmqvist, von Koch, Kostulas, Holm, Widsell, Tegler, Johansson, Almazan and de Pedro-Cuesta (1998) found moderately disabled stroke patients discharged early with home rehabilitation obtained the same clinical results as stroke patients who had rehabilitation in a hospital, day care or outpatient care. In a RCT in Canada, Mayo, Wood-Dauphinee, Cote, Gayton, Carlton, Buttery and Tamblyn (2000) found stroke patients discharged early with home rehabilitation had higher level of

function, greater satisfaction with community integration, and better physical health than those treated with conventional stroke rehabilitation. In Australia, Anderson, Rubenach, Mhurchu, Clark, Spencer and Winsor (2000) found no difference in clinical outcomes between stroke survivors treated with early discharge with home-based rehabilitation compared to conventional stroke rehabilitation. However, for our purposes it is important to note that caregivers of stroke survivors in the home-based rehabilitation had significantly lower mental health scores compared to caregivers of stroke survivors in the conventional rehabilitation group.

#### Research Challenges

Stroke research is complicated by difficulties in measuring the stroke (manifestations, etiology, prognosis and recovery) and by the multitude of scales available but none are universally accepted (D'Olhaberriague, Litvan, Mitsias & Mansbach, 1996). Rehabilitation research is complicated by a lack of standardized universally accepted outcome measures that reflect a conceptual framework of rehabilitation and incorporate the patient's point of view (Wood-Dauphinee, Arsenault & Richards, 1994). Clinical research is limited by declining health-care resources, shorter lengths of stay, general workplace pressures (Fricke, 1993; Loomis, 1994; Wood-Dauphinee et al., 1994) and an emphasis on short-term indicators rather than long-term social outcomes (Batterham, Dunt & Disler, 1996; Ellek, 1996; Ellenberg, 1996).

## Caregiver

#### **General Background**

The fact that community-residing disabled elders receive most of their assistance from family and friends is now accepted without challenge (McKinlay, Crawford & Tennstedt, 1995). Two

American national surveys (1982 and 1982-84) showed that 55-60% of spouse caregivers were the sole care providers of their frail elderly spouses with limited help from other family members or formal sources (Mui, 1995).

Whitlatch, Feinberg and Sebesta (1997) define 'caregiver adaptation' as the ability to adjust psychologically to the demands of providing long-term in-home care. It is well documented that caring for a disabled spouse can create varying levels of emotional, psychological, financial, and familial strain for informal caregivers (Mui, 1995). In a longitudinal study done by McKinlay, Crawford and Tennstedt (1995), 61% of caregivers reported the greatest toll of caregiving affected their personal life (health, sleep, privacy, leisure time, finances, and household management); 18% of caregivers reported the greatest affect was on their family life; and 15-20% reported the greatest affect was on employment.

Most research on caregivers of the elderly (with or without dementia) has focused on the negative emotional aspect of caregiving. However, Jutras and Lavoie (1995) and McKinlay, Crawford, and Tennstedt (1995) point out that research is needed to understand positive aspects of caregiving (such as higher self-esteem, a sense of responsibility or increase in personal control) and on the physical health aspects of caregiving on the caregiver.

## **Caregivers of Stroke Survivors**

Han and Haley (1999) reviewed literature published from 1986 to 1998 on the topic of stroke survivor caregivers. Of the more than 200 articles identified, 20 were empirical articles that focused on the well being of stroke survivor caregivers. From these 20 articles, caregivers could

be described as female<sup>2</sup> (54-93%), spouses (55-100%) or adult children (37%), and between the ages of 56-74 years old (mean ages). Seventeen of the 20 articles reviewed by Han and Haley studied caregiver psychological distress and 7 of these articles studied caregiver depression. Caregiver depression ranging from 34-52% was higher than control groups (12%) or comparable groups (16%). Predictors for caregiver depression included caregiver variables (psychosocial/worry about the future, decrease in social contacts, and more physical health symptoms) and stroke survivor variables (physical disability, depression, and abnormal behavior). Caregiver depression increased with severity of stroke. Caregiver depression impaired the stroke survivor's social rehabilitation. Caregivers relied on family and friends for respite, rather than formal services. Caregivers had fewer social resources than their control group. Caregiver life satisfaction was directly related to caregiver burden, which was in turn related to a patient's level of handicap. Caregiver well-being was related to caregiver physical health, appraisal of caregiving stress, and satisfaction with service provision.

According to Han and Haley (1999), it is important to understand stroke caregiving because more stroke victims are surviving and being discharged home, thereby increasing the numbers of family caregivers coping with stroke. Caregivers need to cope with stroke survivors being discharged home soon after their stroke and with more severe stroke effects. Evidence shows that caregiver adjustment has important implications for stroke survivor quality of life. Anderson, Linto and Stewart-Wynne (1995) note that there are financial constraints in the health care system, a shift from institutional care to community care, a growing number of elderly caregivers, a growing number of working women caregivers, and a reluctance of some family

<sup>&</sup>lt;sup>2</sup> It has been shown statistically, that there are more female caregivers and more male stroke survivors, than the reverse (Bugge, Alexander & Hagen, 1999).

members to provide care. Ultimately the support of family caregivers has an important impact on the stroke survivor's rehabilitation, quality of life, and whether stroke survivors can remain outside of supported care (Han & Haley, 1999; Jongbloed, Stanton & Fousek, 1993; McKinlay, Crawford & Tennstedt, 1995).

## **Caregiver Burden**

Anderson, Linto and Stewart-Wynn (1995) examined the effect of caregiving in a group of personal caregivers to stroke survivors who had support from family (58%), professional help from the community (42%), or both. The majority of caregivers (88%) reported emotional burden, which included anxiety (58%), depression (50%), fear (35%), frustration (32%), resentment (29%), impatience (25%), and guilt (10%). Most caregivers reported adverse effects on their health (79%), disruption in leisure activities (79%), and more than half reported disruption in leisure time (55%). Few stroke caregivers reported disruption in physical health.

The concept of burden can be defined in two ways: impact/objective burden - which refers to the amount of time spent on caregiving or finances; and perceived/subjective burden - which refers to the caregiver's perception of the impact of caregiving-related demands or problems. Research has shown that perceived burden has a major impact on the lives of caregivers (Scholte op Reimer, de Haan, Pijnenborg, Limburg & van den Bos, 1997).

Bugge, Alexander and Hagen (1999) examined stroke caregiver burden using the Caregiver
Strain Index (CSI), which looks at 13 distinct strain factors: 1) overwhelmed, 2) financial strain,
3) work changes, 4) person has changed, 5) behavior is distressing, 6) emotional adjustment,

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7) other time demands, 8) changes to plans, 9) family changes, 10) confining, 11) physical strain,
12) inconvenient, and 13) sleep is disturbed. Their findings suggest that strain factors 8, 9 and
10 were consistently more problematic than other strain factors at 1, 3 and 6 months post-stroke.

Scholte op Reimer, de Haan, Rijnders, Limburg and van den Bos (1998) examined caregiver burden using the Sense of Competence Questionnaire (SCQ). Significantly higher levels of caregiving burden were documented on subscale 3 (consequences of involvement in care for the personal life of the caregiver) compared to subscale 1 (the satisfaction with the impaired person as a recipient of care) or 2 (satisfaction with one's own performance as a caregiver). Using multiple linear regression analysis, 47% of the variance of total caregiver burden was explained. Caregiver emotional distress (16%), loneliness (6%), psychosocial support (4%), caregiver disability (3%), caregiver's unmet IADL care needs (2%), and amount of informal care (2%) explained 33% of caregiver burden. Stroke survivor disability explained 14% or almost onethird of caregiver burden.

Elmstahl, Malmberg and Annerstedt (1996) examined caregiver burden using the Caregiver Burden Scale (CBS), which was based on a theoretical model that describes burden as a decreased feeling of well-being and increased health problems. Interestingly, the highest caregiver burden was found among patients showing the greatest improvement in ADL over a 3-year period. The authors suggest this may be due to the loss of caregiver role over time. Patient extraversion and high quality of life were negatively correlated with caregiver burden. For this research, the CBS was selected to measure caregiver burden.

## Quality of Life

## Health versus Quality of Life

The WHO defines health as a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity. This definition has also been used as a starting point for defining quality of life and health-related quality of life. As a result, the terms health and quality of life are sometimes used interchangeably; for example Solomon, Glick, Russo, Lee and Schulman (1994) state that quality of life can be measured using functional status scales that quantify the physical and emotional health status of patients. However, recent research by Smith, Avis and Assman (1999) and Michalos, Zumbo and Hubley (2000) conclude that quality of life and health status are distinct constructs, and that the two terms should not be used interchangeably. Smith et al. (1999) found that subjects emphasized physical health when rating health status and mental health status when rating quality of life. For this research, health and quality of life were considered two distinct concepts.

#### Health

According to Rokeach (1973), based on American data, health is the most desired and sought after state of being. Despite the centrality of health in our daily lives, the concept is not well defined. Different definitions of health emphasize mortality, daily functioning, and symptomatic complaints (Kaplan, 1985). Health status may also be conceptualized as an extension of functional status measured through activities of daily living performance, body functions, symptoms, emotional status, and cognitive functions (Michalos, Zumbo & Hubley, 2000).

Health outcomes are important in medical research (Kaplan, 1985). There are many health measures available for research, some which have been tested with stroke survivors. One that has achieved such a high status in the research community that it is sometimes referred to as the 'gold standard' for health status measurement is the Medical Outcomes Study Short Form-36 or SF-36 (Michalos, Zumbo & Hubley, 2000) developed by Ware and Sherbourne. The development and underlying logic of the SF-36 are described by Ware and Sherboure (1992). Self-reported health status can be summarized into 8 SF-36 scales (see Table 1) scored from 0 to 100, where a higher score indicates better health (McHorney, Ware & Raczek, 1992). For this research, the SF-36 was selected to be the measure for self-reported health status.

#### Table 1.

Content	oft	the	SF-36	Questionnaire
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Concepts	# of Items	Meaning of Low Score	Meaning of High Score
Physical Functioning	10	Limited a lot in performing all physical activities including bathing or dressing due to health	Performs all types of physical activities including the most vigorous without limitations due to health problems
Role Physical	4	Problems with work or other daily activities as a result of physical health	No problems with work or other daily activities as a result of physical health
Bodily Pain	2	Very severe and extremely limiting pain	No pain or limitations due to pain
General Health	5	Evaluates personal health as poor and believes it is likely to get worse	Evaluates personal health as excellent
Vitality	4	Feels tired and worn out all the time	Full of pep and energy all of the time
Social Functioning	2	Extreme and frequent interference with normal social activities due to physical or emotional problems	Performs normal social activities without interference due to physical or emotional problems
Role Emotional	3	Problems with work or other daily activities as a result of emotional problems	No problems with work or other daily activities as a result of emotional problems
Mental Health	5	Feelings of nervousness and depression all of the time	Feels peaceful, happy and calm all of the time

Source: Ware, Snow, Kosinski & Gandek 1993 and copied from Ware & Sherbourne, 1992

The SF-36 has been used in research with elderly, stroke survivors, or both. The SF-36 was tested for satisfying minimum psychometric requirements and it was found to be appropriate for diverse populations; completion rates were high in all populations but lower among elderly and

those with less than a high school education or those in poverty (McHorney, Ware, Lu & Sherbourne, 1994). McCallum (1995) tested the psychometric properties of the SF-36 in Australia using four groups, no condition, minor medical condition, depressive, and serious medical condition that included the diagnosis of stroke. McCallum found the SF-36 to be a valid measure of general health status. Anderson, Laubscher and Burns (1996) examined the suitability of the SF-36 for stroke survivors. Validity was assessed by comparing stroke survivor SF-36 results to the Barthol Index, the 28-item General Health Questionnaire, and the Adelaide Activities Profile (AAP). Researchers found the SF-36 was a valid measure of physical and mental health after stroke, but found it less able, as compared to the AAP, to measure social activities which were relevant to many elderly patients. The authors recommend using the SF-36 supplemented by other measures.

O'Mahony, Rodgers, Thomson, Dobson and James (1998) tested the SF-36 in England as part of a postal survey for older stroke patients. (The other components of the survey were not reported.) There was an 83% return rate for the SF-36 and a 67 to 96% completion rate for individual items on the SF-36. From this, the researchers concluded the SF-36 should not be used as a postal survey for older stroke patients. McCallum (1995) acknowledges this finding and notes it has not been found elsewhere.

#### Quality of Life

Most rehabilitation professionals would argue that their overall goal is to improve the quality of their patient's life (Wood-Daphinee & Kuchler, 1992). Day (1993) states "the goal of rehabilitation is gradually shifting from restoration of function or integration into the community,

to improving quality of life" (p. 138). Rehabilitation plays a major role in enhancing the quality of life of individuals who have been injured or ill (Wood-Dauphinee & Kuchler, 1992). Interestingly, Mayers (1995) reports that patients are more able to commence adaptation leading to improved quality of life when the occupational therapist engages the client in discussion of what is important to their quality of life. Radomski (1995) states, "from its beginnings, and at its contemporary core, the occupational therapy profession has held good quality of life as the super ordinate aim of therapy" (p. 487).

Evidence suggests that the topic "eudaimonia" or happiness or well-being was of interest to Greek philosophers including Aristotle (384-322 BC) many years ago (Chung, Killingworth & Nolan, 1997). Today, quality of life has become firmly established as an important endpoint in medical care especially for chronic conditions (Smith, Avis & Assman, 1999).

Despite widespread acceptance of the importance of studying quality of life, there is no universally accepted definition (Chung, Killingworth & Nolan, 1997; Mayers, 1995). A literature search done by Schumacher, Olschewski and Schulgen (1991) on quality of life in cancer and oncology patients found considerable heterogeneity in the way quality of life is dealt with in the literature. Wood-Dauphinee and Kuchler (1992) found few articles published on quality of life within rehabilitation journals. Similarly, in a literature search done on quality of life and Occupational Therapy, Mayers (1995) found variable definitions or an absence of definitions among the few articles found. According to Radomski (1995), Zhan's operational definition of quality of life includes four dimensions: life satisfaction, self-concept, health, and functioning. Smith, Avis and Assman (1999) define quality of life in the context of chronic disease as the subjective appraisal of one's current life based primarily on psychological functioning and to a lesser extent on physical functioning. Schumacher, Olschewski and Schulgen (1991) define quality of life as a non-static time-dependent multidimensional construct that is based primarily on the individual patient's perceptions and expectations.

A simple linear model was one of the first models used to explain quality of life. In this model, the independent variables were satisfaction levels with various specific domains of life; and the dependent variable, quality of life, was operationalized as satisfaction with life as a whole, satisfaction with overall quality of life, and happiness with life. Both independent and dependent variables were measured on 7-point scales (Michalos, Zumbo & Hubley, 2000). For the purpose of this study, domain satisfaction was based on 12 aspects of life, quality of life was operationalized as described above, and both were used with stroke survivors and caregivers.

#### Health and Quality of Life of Stroke Survivors and Caregivers

De Haan, Limburg, van de Muelen, Jacob and Aaronson (1995) investigated the relationship between the stroke survivor's quality of life and lesion type and laterality. They used the Sickness Impact Profile (SIP) to measure quality of life. They found that there was no difference in the quality of life for different types of stroke or lesion laterality. The most severely impaired quality of life was related significantly to older age, co-morbidity, stroke severity, and supratentorial lesions. Because the SIP was designed as, and is considered a measure of health

status (Damiano, 1999), another way to interpret these findings is that there was no difference in health status for different types of stroke or stroke laterality, and that poor health was related significantly to older age, co-morbidity, stroke severity, and supratentorial lesions.

Anderson, Laubscher and Burns (1996) investigated the internal consistency and validity of the SF-36 in stroke patients in Adelaide, Australia. The 90 stroke survivors were 1 year post-stroke, between 36-92 years old (mean age of 72 years), represented an almost equal distribution of men (53%) and women (47%), and were willing and able to complete the SF-36. The study found that the SF-36 had internal consistency and validity and recommended it to measure stroke survivor self-reported health. The actual SF-36 results from the study are presented in Table 2.

## Table 2. SF-36 means from two stroke survivor studies

SF-36 Means	PF	RP	BP	GH	VT	SF	RE	MH
a) stroke survivors	48	76	76	64	56	86	83	77
b) stroke survivors	48	65	72	60	47	67	85	81
b) controls	70	78	76	76	62	86	93	85

a) Anderson, Laubscher & Burns, 1996.

b) Hackett, Duncan, Anderson, Broad & Bonita, 2000.

c) Hackett, Duncan, Anderson, Broad & Bonita, 2000.

Each SF-36 subscale scores run from 0-100, higher scores indicate better health.

Hackett, Duncan, Anderson, Broad and Bonita (2000) studied self-reported health status of New Zealand stroke survivors compared to controls. Stroke survivors were 6 years post-stroke, between 25-96 years old (mean age was 71 years), and 49% male. Stroke survivor controls were matched by age and gender. The study found that crude mean scores for stroke survivor self-reported health was significantly lower than controls across all 8 SF-36 domains; results are shown in Table 2. The greatest difference in mean scores was in SF-36 physical function.

Bugge, Alexanader and Hagen (1999) studied caregiver strain and health in Glasgow, Scotland. Caregiver health was assessed using the SF-36 at 1-, 3-, and 6-months after the patient's stroke. On average, caregiver health was worse than published norms for persons aged 55-64 but were not significantly different than age- and sex-matched norms. The actual SF-36 scores were not presented in the article.

Hop, Rinkel, Algra and van Gijin (1998) conducted a study on stroke survivor function and quality of life and their caregivers. There were 64 stroke survivors in the study, all of them had survived a subarachnoid hemorrhage. Tests completed 4 months after the stroke included the Rankin Scale<sup>3</sup>, SF-36, Sickness Impact Profile (SIP), and a visual analogue scale (VAS) which asked how the person did before the stroke and how they are doing now. Researchers reported that stroke survivors who had no loss of function (Rankin Scale grade was 0) had no reduction in quality of life (SF-36, SIP, VAS), while all other stroke survivors, even those who had a good outcome had a reduction in quality of life. Quality of life was especially worse in the physical and psychosocial subscores. Researchers reported that caregivers of the stroke survivors with no loss of function in quality of life scores. Because the SF-36 and the SIP actually measure health status, another way to interpret these findings is that only stroke survivors who had no loss of function, and only caregivers to these stroke survivors, had no reduction in their self-reported health.

<sup>&</sup>lt;sup>3</sup> The Rankin Scale was designed to measure handicap (social disadvantage), but actually measures impairment, disability and handicap (De Haan, Limburg, Bossuyt, van der Meulen & Aaronson, 1995).

Anderson, Rubenach, Mhurchu, Clark, Spencer and Winsor (2000) studied health and other variables in stroke survivors and caregivers in Adelaide, Australia. Eighty-six stroke survivors were randomly assigned to either a home-based or conventional rehabilitation program. Stroke survivors had a mean age of 75 years, 56% were male, and 57% had an identified caregiver. Tests completed with stroke survivors 6 months post-stroke included the SF-36, Barthol Index, Adelaide Activities Profile (AAP), Nottingham Health Profile, Satisfaction with Rehabilitation, and McMaster Family Assessment Device. Stroke survivor results showed that there were no significant differences on any of the tests administered, between stroke survivors who had conventional rehabilitation and those who had home-based rehabilitation. See Table 3 for the SF-36 results. All patients were satisfied with their recovery. All patients were dissatisfied with their understanding about stroke and the information they received from healthcare professionals during the course of rehabilitation. Tests completed with the 49 caregivers were the same as those for stroke survivors, except the Caregiver Strain Index was substituted for the Barthol Index. Caregiver results showed that caregivers of patients in the home-based rehabilitation program had statistically significant lower mean scores on the SF-36 mental health scale, lower SF-36 mental component score, and were less active in household activities, but had higher SF-36 physical component scores, than caregivers of stroke survivors who had conventional rehabilitation. Researchers concluded that home-based rehabilitation programs can reduce hospital utilization but can increase risk of poorer mental health in caregivers.

Table 3.

SF-36 Means of Stroke Survivors who had Home-based or Conventional Rehabilitation and their Caregivers

	Stroke Survivors	Stroke Survivors	Caregivers of	Caregivers of
	Home-Based	Conventional	Home-Based	Conventional
PF	41	43	76	73
RP	71	77	74	61
BP	61	70	67	57
GH	62	67	68	64
VT	54	56	55	58
SF	75	83	75	80
RE	93	93	81	73
МН	81	83	70	82
Physical component score	37	40	47	42
Mental component score	54	56	47	52

Anderson, Rubenach, Mhurchu, Clark, Spencer & Winsor, 2000.

King (1996) looked at the quality of life of stroke survivors 1-3 years post-stroke. Stroke survivors were obtained from the discharge records of two rehabilitation centers in Chicago, U.S.A. There were 86 stroke survivors in the group, 55% were female, 78% were white, and 69% were high school graduates. Quality of life was measured with Ferrans & Powers QOL Index – Stroke Version, which assesses satisfaction with and importance of, health and functioning, socioeconomic, family, and psychosocial domains. The results indicated that overall quality of life of stroke survivors was relatively high and comparable to that of a normal population. Depression, perceived social support, and functional status explained 38% of the variance in quality of life index scores.

A recent Canadian study by Kim, Warren, Madill and Hadley (1999) studied quality of life in stroke survivors 1-3 years post-stroke who were between the ages of 63-86 years (mean age was 75 years). There were 50 stroke survivors in the group, 58% were male, 68% were married, and 56% had graduated from high school or higher education. Quality of life was measured using the

Ferrans & Powers QOL Index-Stroke Version. Overall quality of life was considered moderate, which was lower than in King's (1996) study. Depression, marital status, social support, and functional status accounted for 60% of the variation in quality of life in stroke survivors; depression alone accounted for 32% of the variation in quality of life. Researchers concluded that adaptation to stroke involves much more than physical function and recommend holistic rehabilitation programs.

Robinson-Smith, Johnston and Allen (2000) investigated the relationship between stroke survivor self-care efficacy to functional independence, quality of life, and depression 1- and 6months after stroke. Subjects were obtained from a major rehabilitation center in northeastern U.S.A. There were 77 stroke survivors in the study whose age ranged from 36-92 years (mean age was 71 years), 55% were male, 92% were white, and 76% were high school graduates. In this study, self-care efficacy was measured with the Strategies Used by People to Promote Health (SUPPH), function was measured with the Functional Independence Measure, quality of life was measured with the QOL Index-Stroke Version measure, and depression was measured with the Center for Epidemiologic Studies Depression (CES-D). The results indicated that self-care efficacy increased after stroke and was strongly correlated with quality of life measures and depression at 1 and 6 months post-stroke. Functional independence was modestly correlated with quality of life at 6 months post-stroke. The researchers concluded that self-care efficacy is strongly related to quality of life and to depression, and should be encouraged by family and clinicians.

Radomski (1995) conducted a literature review on stroke survivor quality of life and found that despite making significant improvements (regaining physical status or functional status) following rehabilitation, stroke survivors reported low quality of life, socialization or leisure pursuits 1-3 years post-stroke.

#### Conclusion

There are increasing numbers of stroke survivors being discharged home and being cared for by their personal caregivers. Many of these stroke survivors suffer from negative stroke effects. Many caregivers suffer from caregiver burden, poor health and depression. Studies indicate that stroke survivor health is related to their age, co-morbidity, stroke severity (De Haan, Limburg, van de Meulen, Jacob & Aaronson, 1995), and function (Hop, Rinkel, Algra & van Gijin, 1998) and is lower than the general population (Hackett, Duncan, Anderson, Broad & Bonita, 2000; Bugge, Alexander & Hagen, 1999). Caregiver mental health status was found to be lower for caregivers of stroke survivors who had home-based rehabilitation than caregivers of stroke survivors who had conventional rehabilitation (Anderson, Rubenach, Mhurchu, Clark, Spencer & Winsor, 2000). While King (1996) found the quality of life of stroke survivors to be high and comparable to the general population, Kim, Warren, Madill and Hadley (1999) found it to be moderate and lower than that reported by King. The relationships among function, burden, health, and quality of life, for stroke survivors and their caregivers, is not clear and is the focus of this enquiry.

#### **CHAPTER II**

## **RESEARCH METHODS**

## **Research Objectives**

There were three objectives in this study. The first was to describe community-dwelling stroke survivors who attend a Stroke Recovery Association of B.C. (SRABC) stroke club, their caregivers, and stroke survivor-caregiver dyads. The second was to compare descriptive results to available literature and to analyze relationships among the variables using correlations. The third was to determine the variables that best explained quality of life through multivariate regression.

## **Study Participants**

Study participants were B.C. stroke survivors and caregivers who participated in the study voluntarily and anonymously. A stroke survivor participant was a person who has had a stroke<sup>1</sup>, was community-dwelling (not institutionalized), and attended a SRABC stroke club. A caregiver participant was an unpaid person who helped the stroke survivor in everyday living. Formal paid caregivers were asked not to complete the survey. A stroke survivor-caregiver dyad was a pair whose questionnaire numbers and demographic information matched.

The sample size for study participants was established between the researcher and the supervisor of the study. The goal was to achieve a minimum of 100 pairs of usable

<sup>&</sup>lt;sup>1</sup> Having had a stroke was defined the person being told or believing that he/she has had a stroke; no diagnostic testing of stroke was conducted.

questionnaires. The researcher planned to distribute 200 pairs of questionnaires; this number was revised to 220 pairs after speaking with SRABC stroke club coordinators.

The request for study participants was formalized in a letter to the SRABC (Appendix B). Barry Fondrick, Director of the SRABC short-listed 23 stroke clubs (from the 38 clubs). Clubs were short-listed to obtain study participants from throughout the province (north to south and east to west, large urban centers and small towns, and large and small club sizes).

## Variables

#### Demographics

Stroke survivor demographic data collected included age, gender, education, marital status, occupation, income, length of time since stroke, recovery, and stroke club attendance. Caregiver demographic data included age, gender, education, marital status, occupation, income, how long they have been a caregiver, adjustment, and stroke club attendance.

## **Quality of Life**

Quality of life was operationalized as satisfaction with life as a whole (satisfaction questionnaire item #5), satisfaction with overall quality of life (item #10), and happiness with life as a whole (item #15). Satisfaction was measured on a 7-point scale from '1' very dissatisfied to '7' very satisfied. Happiness was measured on a 7-point scale from '1' very unhappy to '7' very happy (Michalos, Zumbo & Hubley, 2000).
# **Stroke Survivor Function**

Function was measured only with stroke survivors. It was defined as the ability to carry out lower-level functional activities that affect caregiver burden. Stroke survivor function was measured with the Frail Elderly Functional Assessment (FEFA) Questionnaire, a 19-item questionnaire with proven reliability and validity with stroke survivors living in the community (Gloth, Scheve, Shah, Ashton & McKinney, 1999; Gloth, Walston, Meyer & Pearson, 1995). Questions include mobility (items 1, 2, 3, 16), toileting (13, 14, 15), meals (4, 5, 8), dressing (9, 10), bathing (11, 12), hand (17, 18), finance (6), telephone (7), and medication (19). The answers indicate what the person (stroke survivor) 'can do', not what they 'actually do'. The FEFA can be completed by interviewers face-to-face or telephone or by carer proxies. Questions are rated on a 2-, 3-, 4-, or 5-point scale starting at 'a' equal to '0'. On #19, medication, both 'a' for 'independent' and 'd' for 'not applicable' score 0. The overall design of the instrument was to be used as a wide measure of function, therefore, only the total score is used, not individual scores or sub-categories (Gloth, Scheve, Shah, Ashton & McKinney, 1999; Gloth, Walston, Meyer & Pearson 1995).

### **Caregiver Burden**

Caregiver burden was measured only with caregivers. It was defined as the perception of the impact of caregiving. Caregiver burden was measured with the Caregiver Burden Scale (CBS). Developed in Sweden, the CBS was derived from a theoretical model that describes burden as a decreased feeling of well-being and increased health problems. It

is composed of 22 questions answered on a 4-point frequency scale: not-at-all, seldom, sometimes, and often. Caregiver burden can be described by one total caregiver burden mean score or by 5 factor analytically derived indices named according to the item with the highest loading (general strain, isolation, disappointment, emotional involvement, and environment). The CBS has been evaluated and showed good construct validity and test-retest stability (Elmstahl, Malmberg & Annerstedt, 1996).

### Health

Health was measured for stroke survivors and caregivers. Health was defined as the individual's perceived health status and was measured using the SF-36. The SF-36 has proven reliability and validity and is recommended for measuring stroke survivor health. The SF-36 was constructed to be self-administered by persons over 14 years of age or to be administered by a trained interviewer by phone or in person. Respondents answer the 36 questions rated on a 2-, 3- or 5-point scale by circling a number or placing a tick on a line (McCallum, 1995). The results of the SF-36 are summarized into eight health concepts (physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional, and mental health) (Ware & Sherbourne, 1992) or two subscales (mental health and physical health) (McHorney, Ware & Raczek, 1992). The meanings of low scores and high scores for the eight categories are presented in Table 1.

### **Domain Satisfaction**

Domain satisfaction was measured for stroke survivors and caregivers. It was defined as level of satisfaction in 12 domains: housing, neighborhood, family relations, living partner,

job, friendships, health, religion/spirituality, financial security, recreation, self-esteem, and overall standard of living. It was measured on a 7-point scale ranging from '1' very dissatisfied to '7' very satisfied (Michalos, Zumbo & Hubley, 2000).

# Procedures

# **Ethical Review**

The research proposal had academic approval from the University of Northern British Columbia Research Ethics Review Board and was supported by the Director of the Stroke Recovery Association of British Columbia (SRABC).

# **Design of the Questionnaires**

From the literature reviewed, the researcher chose a combination of existing measures with proven validity and reliability, to collect quantitative data. Where it was possible, the same measurement tool was used to measure the same variable, in stroke survivors and caregivers. The Stroke Survivor Quality of Life Questionnaire collected information about the stroke survivors' function, health, satisfaction, quality of life, and demographics (Appendix E). The Caregiver Quality of Life Questionnaire collected information about the caregivers' burden, health, satisfaction, quality of life, and demographics (Appendix F). An information sheet accompanied each pair of questionnaires (Appendix D). Stroke survivor and caregiver questionnaires were each numbered from 1-220. They were distributed as a matching pair, for example, stroke survivor questionnaire #1 was matched with caregiver questionnaire #1. Practical considerations resulted in a size 12-font for the text, an emphasis on circling or ticking an

answer instead of writing, color coding each questionnaire and the information sheet, and the permission to get help as long as the answer provided was the respondent's.

### **Pilot Study**

The questionnaires were pilot-tested on 6 stroke survivors attending an Out-Patient Neurological Rehabilitation Program at the Prince George Regional Hospital and their 6 caregivers. Stroke survivors and caregivers were asked to complete their questionnaire noting the length of time to complete and any problems such as a lack of clarity, difficult instructions, and spelling errors. On average it took 20 minutes (range 15-40 minutes) to complete either questionnaire. Respondents commented that there was redundancy in some of the questions, but changes were not made to the standardized tests.

#### **Data Collection and Analysis**

The researcher telephoned 21 stroke club coordinators (of 23 short-listed clubs) and described the research project. On April 28, 2001 the researcher mailed packages to stroke club coordinators containing a letter (Appendix C), information sheets (Appendix D), questionnaires (Appendix E & F), and a pre-addressed pre-paid envelope. A total of 220 stroke survivor questionnaires and 220 caregiver questionnaires matched by number were distributed throughout B.C. Stroke club coordinators distributed information sheets and questionnaires to potential study participants. Study participants read the information sheet, completed their respective questionnaire, and returned completed questionnaires to their club coordinator. Club coordinators collected questionnaires up until September 2001 and returned them by mail to the researcher using the envelope provided. The

researcher submitted returned questionnaires to the staff in the Office of the Institute for Social Research and Evaluation. Institute staff entered raw data into Excel to produce descriptive statistics. Descriptive statistics calculated for each question on the questionnaires included: *N* the total number of respondents who answered the question, the mean, standard deviation, and the percentage (%) of respondents that chose that answer. SPSS was used with the Excel data-sets to produce bivariate and multivariate analysis.

### **CHAPTER III**

### **DESCRIPTIVE STATISTICS**

The first objective of this study was to describe community-dwelling stroke survivors who attend a Stroke Recovery Association of B.C. (SRABC) stroke club, their caregivers, and stroke survivor-caregiver dyads. Three data-sets were used to describe these three groups. Table 4 shows the distribution of questionnaires that compose these three data-sets.

### **Stroke Survivor Descriptive Statistics**

The B.C. stroke survivor data-set (N=121), composed of 103 stroke survivor questionnaires as part of a dyad plus 18 single questionnaires, was used for stroke survivor-only analyses. The stroke survivor group was described according to their demographics, function, health, domain satisfaction, and quality of life.

### **Stroke Survivor Demographics**

Table 5 shows B.C. stroke survivor demographics. At least 80% of stroke survivor respondents answered demographic questions. The average age of stroke survivors was 70 years and ranged from 30-93 years. Two stroke survivors were between the ages of 30-44 years, 26 were between 45-64 years, and 65 were 65 and older. More of the stroke survivors were male (62%) than female. Most had grade 8-12 education (63%), 17% had college, and 14% had university level education. Most were married (77%), 15% were widowed, 3% were divorced or separated, and 2% were common-law. Most were retired (93%), 8% were homemakers, 5% were volunteers, and 3% labeled themselves as disabled<sup>1</sup>. Most had incomes below \$30,000 (68%), 14% had an income between \$30-40,000, 6% between \$40-

<sup>&</sup>lt;sup>1</sup> The category of 'disabled' was not on the original questionnaire. It was added in as a category by some of the respondents. The 2.5% would be an underestimate of the number of 'disabled' stroke survivors.

50,000, 4% between \$50-60,000, and 7% over \$60,000. Ninety-two percent had a caregiver as defined for this study. Stroke survivors rated their adjustment to living with a stroke as 73% (range was 0-100%), where 0% meant no adjustment and 100% meant full adjustment.

### Stroke Survivor Stroke and Therapy

Details about the stroke and therapy were presented in Table 6. No fewer than 92% and no more than 96% of B.C. stroke survivors answered questions in this section. The average length of time since having a stroke was 71 months (6 years) with a range of 6-288 months. The right side of the body was affected in 53% of stroke survivors and left side in 47% of stroke survivors. Ninety-four percent of stroke survivors had some form of therapy, defined on the questionnaire as occupational therapy, physiotherapy, speech language pathology, and recreation therapy, while six percent reported that they had no form of therapy. For those who had therapy, it was provided through at least one of the following (respondents could choose more than one category), 78% of stroke survivors had therapy in a hospital, 54% in a rehabilitation unit, 55% in outpatients, and 15% in home care.

# Stroke Survivor Stroke Club Attendance

Stroke club attendance by B.C. stroke survivors was presented in Table 7. Most respondents (99%) answered questions related to stroke club attendance. Of those who answered the question, 99% attended a stroke club with an average attendance of 45 times per year (range 0-150 times per year) and on average they had been attending a stroke club for 54 months (range 1-204 months).

18 singles

returned

8 singles

returned

103 pairs\*\* =

206 returned

	Stroke Club Name	The series of	The # of paired	The # of paired	The # of single	The # of single
		#'s on the question-	questionnaires sent April 28/01	questionnaires returned by	stroke survivor questionnaires	questionnaires
-		naires	-	Sept/01	returned	returned
1	Burnaby North	1-5	5	4	1	
2	Chilliwack	6-11	6	2		
3	Comox Valley	12-16	5	2	3	
4	Coquitlam	17-36	20	17		
5	Grand Forks	37-38	2	2		
6	Kelowna	39-48	10			
7	Langley	49-58	10	3	1	
8	North Shore	59-68	10	9		
9	Parksville	69-83	15	6	1	
10	Saanich	84-93	10	10		
11	Prince George	94-99	6	5		
12	Ridge Meadows	100-114	15			
13	Salmon Arm	115-124	10	5	1	
14	South Delta	125-144	20	3		
15	Trail	145-149	5	3		
16	Vanc-Shaughnessy	150-156	7	4		1
17	Vanc-Templeton	157-164	8			
18	Vanc-West End	165-184	20	1	4	
19	Vanderhoof	185-190	6	3		
20	Victoria	191-200	10	9		1
21	White Rock	201-220	20	15	1	
					6***	6***

Table 4.		
Questionnaires Mailed to and	Returned from	Stroke Clubs in B.C.

Questionnaires Sent:

\*220 stroke survivor + 220 caregiver questionnaire dyads were sent for a total of 440 questionnaires

440 sent

220 pairs\* =

Questionnaires Returned:

Stroke Survivor-Caregiver Data-set = 103 pairs

\*\*103 stroke survivor + 103 caregiver matched questionnaires returned for a total of 206 questionnaires; 103/220 = 47%

Stroke Survivor Data-set = 121 individual stroke survivor questionnaires 103 stroke survivor questionnaires, as part of a dyad, + 18 single stroke survivor questionnaires = 121; 121/220 = 55%

Caregiver Data-set = 111 individual caregiver questionnaires

103 caregiver questionnaires, as part of a dyad, + 8 single caregiver questionnaires = 111; 111/220 = 50%

\*\*\*Returned as a pair but the data suggested single as information did not match

N	%	Personal Information		%
117	97	Age	30-44 years old	2
		(Range 30-93 years old)	45-64 years old	26
		(Mean 70 years old)	65 and older	76
120	99	Gender	Female	39
			Male	62
120	99	Education	Grade 1-7	7
			Grade 8-12	63
			College/Technical	17
			University	14
121	100	Marital Status	Married	77
			Common law partner	2
			Single	1
			Widowed	15
			Divorced	3
			Separated	3
121	100	Employment	Employed	1
			Own Business	1
			Retired	93
			Homemaker	8
			Student	0
			Volunteer	5
			Disabled*	3
97	80	Income/per year	Less than < \$20,000	36
			\$20-30,000	32
			\$30-40,000	14
			\$40-50,000	6
			\$50-60,000	4
			over \$60,000	7
20	99	Has a caregiver	Yes	92
			No	8
02	84	Adjustment to stroke,	0-100%, where	73
		Self-rated	0 = not adjusted	
			100 = fully adjusted	

Table	e 5.				
B.C.	Stroke	Survivor	Demographics	(N =	121)

\* = an Employment category named 'Disabled' which was not on the original questionnaire was added during the analysis since some respondents wrote it in themselves. All % values were rounded off to full percent. Table 6.

B.C. Stroke Survivor Stroke & Therapy (N = 121)

N	%	Stroke/Therapy	Range - Months	Mean – Months Year	SD	%
114	94	Time since stroke – months - years	6-288	71 6	54.7	
111	92	Left arm/leg affected Right arm/leg affected				47 53
116	96	No therapy				6
		Therapy in Hospital	0.5 - 12.0	2.4	2.0	78*
		Therapy in Rehab Unit	0.5 - 24.0	3.3	3.4	54*
		Therapy in Outpatient	0.5 - 42.0	6.6	9.2	55*
		Therapy in Home Care	1.0 - 60.0	12.2	17.7	15*

\*= the total % for therapy exceeds 100% because respondents chose more than 1 category . All % values rounded off to full percent.

Table 7. B.C. Stroke Survivor Stroke Club Attendance (N = 121)

N	%	Attends	%	Range	Mean	SD
120	99	No	1			
		Yes	99			
		How often - times/year		0-150	45	28
		How long – months		1-204	54	49
		- years			4 ½ yrs	

All % values rounded off to full percent.

Other values rounded to full integer.

# **Stroke Survivor Function**

The results for the Frail Elderly Functional Assessement (FEFA) were presented in Table 8. At least 97% of B.C. stroke survivors answered the 19 questions on the FEFA, which are rated on 2-, 3-, 4- or 5-point scales, starting at zero. Low scores indicate independence whereby 0, the lowest total score equates with full independence. High scores indicate dependence whereby 55, the highest total score equates with complete dependence. The mean total FEFA score for B.C. stroke survivors was 8.1 +/- 7.1, which was closer to the independence end of the scale. Only the composite total mean FEFA score was used in analyses.

The following describes the main findings for each FEFA question for the group of stroke survivors. On question 1, 56% of stroke survivors could walk with a cane or walker and 32% could walk without any help. The group's mean score was 0.9 on a scale of 0-3. For question 2, 83% of stroke survivors could transfer out of bed without any assistance device. The group's mean score was 0.4 on a scale of 0-4. For question 3, 92% of stroke survivors could turn over on their side in bed without help. The mean score was 0.2 on a scale of 0-3. For question 4, 67% of stroke survivors could wash dishes. The mean score was 0.3 on a scale of 0-1. For question 5, 41% of stroke survivors could prepare their own hot dinner and 29% could heat up prepared meals. The mean score was 1.1 on a scale of 0-3. For question 6, ability to manage money, 42% of stroke survivors could manage their money, 22% could not manage their money but not major bills and balancing a check book, 22% could not manage their money, and 15% could sign checks but could not handle minor transactions. The mean score was 1.2 on a scale of 0-3. For question 7, 83% of stroke survivors could use the telephone independently including dialing and answering. The mean score was 0.3 on a

scale of 0-3. For question 8, 95% of stroke survivors could feed themselves by mouth without help. The group's mean score was 0.1 on a scale of 0-4. For question 9, 70% of stroke survivors could dress independently in day clothes if placed out and 20% required help from another person. The mean score for dressing in day clothes was 0.6 on a scale of 0-3. On question 10, 83% of stroke survivors could dress independently in nightclothes if placed out and 13% required help from another person. The mean score for dressing in nightclothes was 0.4 on a scale of 0-3. For question 11, 49% of stroke survivors could bathe in a tub or shower without help, 17% could with assistive devices, and 15% required help from another person. The group's mean score was 1.2 on a scale of 0-4. Only 13 respondents were required to answer question 12. Of these, 7 stroke survivors could sponge bathe with help from another person, 5 were completely dependent on another person, and 1 was completely independent. On question 13, 83% of stroke survivors were independent with toileting, including getting to the bathroom. The group's mean score was 0.3 on a scale of 0-3. Questions 14 and 15 were not applicable, as no respondents had selected 13 e. For question 16, 95% of stroke survivors could sit up without help. The group's mean score was 0.1 on a scale of 0-3. For question 17, 49% of respondents could grasp a cup or cloth in either hand and 51% could with one hand. The group's mean score was 0.5 on a scale of 0-2. For question 18, 86% of stroke survivors could reach out past their nose with arm fully extended at shoulder level. The group's mean score was 0.2 on a scale of 0-2. For the last question, 56% of respondents could take daily medication without help and 35% could if another person set it out. The group mean for taking medication was 0.5 on a scale of 0-2.

n	%	Frail Elderly Functional	% of respondents choosing:				Mean	SD	
		Assessment (FEFA) items	a	b	c	d	e		
119	98	1. Walk	32	56	7	6		0.9	0.8
117	97	2. Transfer-in/out bed	83	7	6	1	3	0.4	0.9
119	98	3. Turn over in bed	92	3	2	3		0.2	0.6
119	98	4. Wash dishes	67	33				0.3	0.5
119	98	5. Prepare hot dinner	41	29	12	19		1.1	1.1
121	100	6. Manage money	42	22	15	22		1.2	1.2
121	100	7. Use telephone	83	8	3	7		0.3	0.8
121	100	8. Eat by mouth	95	4	1	0	0	0.1	0.3
121	100	9. Dress self/clothes laid out	70	6	20	4		0.6	1.0
120	99	10. Dress self/bed clothes laid out	83	0	13	5		0.4	0.9
121	100	11. Bath or shower	49	17	15	9	11	1.2	1.4
11	9	12. Sponge bath	8	54	39			1.3	0.6
120	99	13. Use the toilet	83	8	7	3		0.3	0.7
Na		14. Bedside commode							
Na		15. Use a bedpan/urinal							
117	97	16. Sit up	95	3	2	1		0.1	0.4
119	98	17. Grasp	49	52	0			0.5	0.5
118	98	18. Upper Extremity Reach	86	13	27			0.2	0.4
119	98	19. Self medicate	56	35	8	1		0.5	0.7
								Total	
		The total of the mean scores for the whole group.						8.1	7.1

# Table 8.

B.C. Stroke Survivor Function (N = 121)

Individual FEFA - low score means independence; high score means dependence.

Total FEFA - lowest score for test is 0 (independence); highest score is 55 (dependence).

All % were rounded off to full integer; means and SD were rounded off to first decimal.

The scoring key is as follows for each question #:

	Y								
# 1.	# 2.	#3.	#4.	# 5.	# 6.	#7.	# 8.	# 9.	# 10.
a = 0	a = 0	a = 0	a = 0	a = 0	a = 0	a = 0	a = 0	a = 0	a = 0
b = 1	b = 1	b = 1	b = 1	b = 1	b = 1	b = 1	b = 1	b = 1	b = 1
c = 2	c = 2	c = 2		c = 2	c = 2	c = 2	c = 2	c = 2	c = 2
d = 3	d = 3	d = 3		d = 3	d = 3	d = 3	d = 3	d = 3	d = 3
	e = 4						e = 4		
# 11.	# 12.	# 13.	# 14.	# 15.	# 16.	# 17.	# 18.	# 19.	
a = 0	a = 0	a = 0	a = 0	a = 0	a = 0	a = 0	a = 0	a = 0	
b = 1	b = 1	b = 1	b = 1	b = 1	b = 1	b = 1	b = 1	b = 1	
c = 2	c = 2	c = 2	c = 2	c = 2	c = 2	c = 2	c = 2	c = 2	
d = 3		d = 3	d = 3	d = 3	d = 3			d = 0*	
e = 4			e = 4						

\*One stroke survivor out of the 121 selected 19 d, which corresponded with the response that he/she 'does not take medication on a daily basis' therefore question 19 was not applicable for this one respondent.

# **Stroke Survivor Health**

Self-reported health status for B.C. stroke survivors is presented in Tables 9 and 10. More than 88% of stroke survivors completed the SF-36 questions. Table 9 shows raw results, which were recoded, scaled, and transformed using SPSS; missing datum were handled by mean substitution. Table 10 shows the B.C. stroke survivor's SF-36 results, whereby the mean score for physical function was 33, role physical 30, bodily pain 62, general health 55, vitality 44, social function 64, role emotion 53, and mental health 69.

# **Stroke Survivor Domain Satisfaction**

Domain satisfaction for B.C. stroke survivors was presented in Table 11. Other than question 6, no less than 72% and no more than 97% of respondents answered 11 questions. Only 7% of stroke survivors responded to question 6, job satisfaction, thus it was removed in subsequent analyses and tables. Stroke survivor mean scores for satisfaction with: home was 5.9, neighborhood 6.0, family relations 5.9, living partner 6.4, job 4.9, friendships 5.4, health 4.4, spiritual fulfillment 5.5, financial security 5.4, recreation activities 4.4, self esteem 5.0, and overall standard of living 5.6.

### Stroke Survivor Quality of Life

Quality of life of B.C. stroke survivors was presented in Table 12. For satisfaction with life as a whole, 95% of stroke survivors responded, and the mean score was 5.2 whereby 1 is very dissatisfied and 7 is very satisfied. For satisfaction with quality of life, 91% of stroke survivors responded, and the mean score was 4.8. For happiness with life as a whole, 92% of stroke survivors responded, and the mean score was 5.1 whereby 1 is very unhappy and 7 is very happy.

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B.C.	Stroke	Survivor	Health	- SF-36	Individual/Raw	Results (	(N = 121)	)
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Q#	SF-36	n	%	Items	Mean	SD	%Yes	% No
3a.	PF1	111	92	Vigorous activity	1.4	0.6		
3b.	PF2	114	94	Moderate activity	1.6	0.7		
3c.	PF3	112	93	Lift/carry groceries	1.6	0.7		
3d.	PF4	111	92	Climb several flights	1.6	0.7		
3e.	PF5	108	89	Climb 1 flight of stairs	1.8	0.7		
3f.	PF6	113	93	Bend/kneel/stoop	1.7	0.7		
3g.	PF7	109	90	Walk>1.6 km/1.0m	1.6	0.8		
3h.	PF8	111	92	Walk several blocks	1.8	0.8		
3i.	PF9	106	88	Walk 1 block	2.0	0.8		
3j.	PF10	117	97	Bath or dress self	2.0	0.7		
4c.	RP1	111	92	Limited in kind of activities			79	21
4a.	RP2	108	89	Limited in time doing activities			48	52
4b.	RP3	113	93	Accomplished less			75	25
4d.	RP4	112	93	Difficulty performing			79	21
7.	BP1	121	100	Intensity of body pain	2.9	1.4		
8.	BP2	118	98	Extent pain interferes	2.2	1.2		
1.	GH1	119	98	Self-rated health	3.2	1.0		
11d.	GH2	117	97	My health is excellent	3.1	1.4		
11b.	GH3	118	98	As healthy as others	2.8	1.3		
11a.	GH4	117	97	Get sick easier than others	3.8	1.3		
11c.	GH5	118	98	Health will worsen	3.2	1.1		
9a.	VT1	116	96	Full of pep	4.3	1.4		
9e.	VT2	111	92	Have a lot of energy	4.1	1.4		
9g.	VT3	117	97	Feel worn out	3.8	1.4		
9i.	VT4	121	100	Feel tired	3.5	1.3		
10.	SF1	119	98	Often interferes social activities	3.7	1.2		
6.	SF2	116	96	Extent interferes social activities	2.5	1.3		
5a.	RE1	105	87	Reduce time doing activities			43	57
5b.	RE2	112	93	Accomplished less			57	43
5c.	RE3	104	86	Not as careful			43	57
9b.	MH1	113	93	Been a nervous person	4.8	1.4		
9c.	MH3	118	98	So down in dumps nothing helps	4.7	1.3		
9d.	MH5	113	93	Felt calm & peaceful	3.3	1.4		
9f.	MH2	114	94	Felt downhearted/blue	4.7	1.2		
9h.	MH4	117	97	Been a happy person	2.8	1.3		
2.	TRAN	118	98	Compare health 1-yr ago	2.8	1.0		

All % values were rounded off to full percent. All means and SD were rounded off to first decimal.

Table 10.

B.C. Stroke Survivor Health - SF-36 Summary Means (N = 121)

SF-36 category and	initials	Mean	SD
Physical function	PF	33	24
Role physical	RP	30	33
Bodily pain	BP	62	26
General health	GH	55	22
Vitality	VT	44	20
Social function	SF	64	27
Role emotional	RE	53	41
Mental health	MH	69	16

Summary scores = raw scores that were recoded, scaled and transformed using SPSS. Missing values replaced by means.

Scale between 0-100, higher score means better health status.

Table 11.

B.C. Stroke Survivor Domain Satisfaction (N = 121)

N	%	Domains of Satisfaction (# on questionnaire)	Mean	SD
114	94	Your home (#1)	5.9	1.6
116	96	Your neighborhood as a place to live (#2)	6.0	1.5
116	96	Your family relations, generally (#3)	5.9	1.6
94	78	Your living partner (eg spouse) (#4)	6.4	1.3
9	7	Your job (#6)	4.9	2.2
114	94	Your friendships (#7)	5.4	1.7
114	94	Your health (#8)	4.4	1.9
87	72	Your religion or spiritual fulfillment (#9)	5.5	1.7
114	94	Your financial security (#11)	5.4	1.5
106	88	Your recreation activities (#12)	4.4	1.7
113	93	Your self esteem (#13)	5.0	1.8
117	97	Your overall standard of living (#14)	5.6	1.4

Scale between 1-7, where 1 is very dissatisfied, and 7 is very satisfied.

# Table 12.

B.C. Stroke Survivor Quality of Life (N = 121)

N	%	Domains of Quality of Life (questionnaire #)	Mean	SD
115	95	Satisfaction with life as a whole (#5)	5.2	1.6
110	91	Satisfaction with overall quality of life (#10)	4.8	1.7
111	92	Happiness with life as a whole	5.1	1.5

Satisfaction: scale between 1-7, where 1 is very dissatisfied, and 7 is very satisfied. Happiness: scale between 1-7, where 1 is very dissatisfied, and 7 is very satisfied.

QUALITY OF LIFE

# **Caregiver Descriptive Statistics**

The B.C. caregiver data-set (N=111), composed of 103 stroke survivor questionnaires as part of a dyad plus 8 single questionnaires, was used for caregiver-only descriptive statistics and analysis. The caregiver group was described according to their demographics, burden, health, domain satisfaction, and quality of life.

### **Caregiver Demographics**

Table 13 shows B.C. caregiver demographics. No less than 78% and no more than 98% of B.C. caregivers answered personal information questions. The average age of the caregivers was 65 years and ranged from 24-84 years. One caregiver was under the age of 29 years, 8 were between 30-44 years, 32 were between 45-64 years, and 68 were 65 and older. More caregivers were female (74%) than male. Most had grade 8-12 education (57%), 26% had college/technical, and 16% had university level education. Most were married (92%), 5% were single, and 2% were divorced or common-law. Most caregivers were retired (69%), 36% were homemakers, 16% were volunteers, 14% were employed, and 2% were disabled<sup>2</sup>. Most had an income below \$30,000 (63%), 17% had an income between \$30-40,000, 9% between \$40-50,000, 2% between \$50-60,000, and 8% over \$60,000. Most caregivers were the spouses of the stroke survivor (87%) and 11% were an adult child of the stroke survivor. Caregivers rated their adjustment to their role of caregiver as 83% (range was 35-100%), where 0% meant no adjustment and 100% meant full adjustment.

<sup>&</sup>lt;sup>2</sup> The category of 'disabled' was not on the original questionnaire. It was added by some of the respondents. The 1.9% would be an underestimate of the number of caregivers who select this category.

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B.C. Caregiver Demographics (	N =	111)	)
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n	%	Personal Information		%
109	98	Age	< 29	0
		(Range 24-84 years old)	30-44 years old	7
		(Mean 65 years old)	45-64 years old	29
			65 and older	62
109	98	Gender	Female	74
			Male	26
109	98	Education	Grade 1-7	2
			Grade 8-12	57
			College/Technical	26
			University	16
109	98	Marital Status	Married	92
			Common-law partner	2
			Single	5
	1		Widow	0
			Divorced	2
			Separated	0
107	96	Employment	Employed	14
			Own Business	3
			Retired	69
			Homemaker	36
			Student	2
			Volunteer	16
			Disabled*	2
87	78	Income	Less than < \$20,000	33
			\$20-30,000	30
			\$30-40,000	17
			\$40-50,000	9
			\$50-60,000	2
			over \$60,000	8
109	98	Relationship of the caregiver	Spouse/common law partner	87
		to stroke survivor	Adult child	11
			Parent	1
			Sibling	0
			Relative	0
			Friend/neighbour	1
101	91	Adjustment to caregiver role.	0-100%, where	83
		Self-rated	0 = not adjusted	
			100 = fully adjusted	

\*= a category named 'Disabled' not on the original questionnaire was added during the analysis since some respondents wrote it in themselves All % values rounded off to full percent.

# **Caregiver Preparation**

Table 14 shows caregiver preparation. No less than 95% and no more than 97% of B.C. caregivers responded to caregiver preparation questions. On average, people had been caregivers for an average of 71 months (almost 6 years). Looking back, 59% of caregivers felt they were not prepared for being a caregiver to a person who had a stroke, 22% were somewhat prepared, 16% were mostly prepared, and 3% were very prepared. The mean score for preparation was 1.63 on a scale of 1-4. Eighty-five percent of caregivers used at least one of the resources listed to prepare for the role of caregiver, 61% used medical staff, 57% used the SRABC stroke club, 48% used educational materials, and 45% talked to others. Fifteen percent did not use the resources listed to prepare for being a caregiver.

### **Caregiver Stroke Club Attendance**

Stroke club attendance by B.C. caregivers is presented in Table 15. Ninety-seven percent of caregivers responded to stroke club attendance questions. Of those caregivers who answered, 71% attended a stroke club with an average attendance of 44 times per year (range 3-150 times per year) and on average had been attending for 66 months (range 1-216 months).

### **Caregiver Burden**

Table 16 shows mean Caregiver Burden Scale (CBS) results for B.C. caregivers. At least 96% of caregivers answered the 22 questions on the CBS that are rated on a scale from 1-4 where low scores mean low burden and high scores mean high burden. The mean CBS total score for B.C. caregivers was 2.2. The mean general strain score was 2.4, for isolation it was 2.3, for disappointment it was 2.2, for emotional involvement it was 1.8, and for environment it was 1.7.

Table 14. B.C. Caregiver Preparation (N = 111)

n	%	Caregiver Preparation	Range	Mean	%
106	95	How long been a caregiver to the stroke survivor	5-216 months	71 months or about 6 yrs	
107	96	How prepared to be a caregiver:	1-4	Mean 1.6	
		%: 1 Not prepared			59
		2 Somewhat prepared			22
		3 Mostly prepared			16
		4 Very prepared			3
108	97	% who used 1 or more of:			85
		Medical staff			61 *
		Materials			48 *
	1	Talk with others			45 *
		Stroke Club			57 *
		% who used none of above:			15

\*adds up to more than 100% as respondents reported more than one way to prepare. All % values rounded off to full percent.

Table 15. B.C. Caregiver Stroke Club Attendance (N = 111)

N	%	Attends	%	Range	Mean	SD
108	97	No	29			
		Yes How often How long	71	3-150 times/year 1-216 months	44 times/year 66 mo/~5 ½ years	23 56

All % values rounded off to full percent.

Other values rounded to full integer.

Table 16.

B.C. Caregiver Burden (N = 111)

Q#	Caregiver Burden Scale (CBS)	n	%	Mean	SD
	Total Burden Mean			2.2	
	General Strain Mean			2.4	
1.	Practical problems	107	96	2.4	0.8
2.	Too much responsibility	109	98	2.5	1.0
3.	Feel like running away	109	98	2.3	1.0
4.	Tired and worn down	111	100	2.8	0.9
5.	Tied down by relatives problems	111	100	2.5	1.0
6.	Mentally trying	110	99	2.5	1.0
7.	Health suffered	110	99	2.1	1.0
8.	Insufficient time for self	109	98	2.5	1.0
	Isolation Mean			2.3	
9.	Avoid inviting friends/acquaintances	111	100	1.7	1.0
10.	Lessened social life	111	100	2.5	1.1
11.	Prevent you from doing what you planned	109	98	2.8	1.0
	Disappointment Mean			2.2	
12.	Life has treated you unfairly	111	100	1.9	0.9
13.	Expected life to have been different	110	99	3.0	0.9
14.	Lonely and isolated	111	100	2.0	1.0
15.	Physically trying	111	100	2.3	1.0
16.	Economic sacrifice	109	98	1.7	1.0
	Emotional Involvement Mean			1.8	
17.	Ashamed of relative's behavior	110	99	1.4	0.7
18.	Offended or angry by relative's behavior	111	100	2.3	0.9
19.	Embarrassed by relative's behavior	111	100	1.7	0.8
	Environment Mean			1.7	
20.	Physical environment makes it difficult	110	99	1.7	0.8
21.	Worry about not giving care in proper way	111	100	2.1	1.0
22.	Anything in neighborhood that makes it difficult	109	98	1.3	0.6

Frequency of burden scale 1-4: 1 = not at all, 2 = seldom, 3 = sometimes, and 4 = often.Lower individual score '1' means less burden; higher score '4' means more burden. Lowest CBS score for test is 22; highest possible total score = 88.

All % were rounded off to full integer; all means and SD rounded off to first decimal.

# **Caregiver Health**

Self-reported health status for B.C. caregivers was presented in Tables 17 and 18. At least 95% of caregivers answered the SF-36 questions. Table 17 shows raw results for all questions, which were recoded, scaled and transformed using SPSS; missing datum were handled by mean substitution. Table 18 shows B.C. caregiver's SF-36 results, whereby the mean score for: physical function was 77, role physical 56, bodily pain 66, general health 63, vitality 53, social function 77, role emotion 67, and mental health 72.

### **Caregiver Domain Satisfaction**

Domain satisfaction for B.C. caregivers was presented in Table 19. Other than question 6, no fewer than 78% and no more than 98% of caregivers answered the remaining 11 questions. Since only 29% of caregivers responded to question 6, job satisfaction, it was removed from subsequent analyses and tables. Caregiver mean scores for satisfaction with: home was 5.9, neighborhood 6.1, family relations 5.7, living partner 6.0, job 5.5, friendships 5.8, health 5.1, spiritual fulfillment 5.6, financial security 5.5, recreation activities 4.6, self esteem 5.3, and overall standard of living 5.8.

# **Caregiver Quality of Life**

Quality of life of B.C. caregivers is presented in Table 20. For satisfaction with life as a whole, 97% of caregivers responded, and the mean score was 5.6 whereby 1 is very dissatisfied and 7 is very satisfied. For satisfaction with quality of life, 96% of caregivers responded, and the mean score was also 5.6. For happiness with life as a whole, 96% of caregivers responded, and the mean score was 5.3 whereby 1 is very unhappy and 7 is very happy.

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B.C. Caregiver Health - SF-36 Individual/Raw I	Results (	N = 1	.11)	
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Q#	SF-36	N	%	Items	Mean	SD	% Yes	% No
3a.	PF1	108	97	Vigorous activity	2.0	0.7		
3b.	PF2	109	98	Moderate activity	2.5	0.7		
3c.	PF3	110	99	Lift/carry groceries	2.5	0.7		
3d.	PF4	111	100	Climb several flights	2.4	0.7		
3e.	PF5	109	98	Climb 1 flight of stairs	2.6	0.6		
3f.	PF6	111	100	Bend/kneel/stoop	2.2	0.7		
3g.	PF7	110	99	Walk>1.6 km/1.0m	2.3	0.8		
3h.	PF8	110	99	Walk several blocks	2.6	0.6		
3i.	PF9	107	96	Walk 1 block	2.9	0.4		
3j.	<b>PF10</b>	109	98	Bath or dress self	2.9	0.4		
4c.	RP1	106	95	Limited in kind of activities			31	69
4a.	RP2	105	95	Limited in time doing activities			56	44
4b.	RP3	107	96	Accomplished less			40	60
4d.	RP4	106	95	Difficulty performing			45	55
7.	BP1	109	98	Intensity of body pain	2.8	1.3		
8.	BP2	109	98	Extent pain interferes	2.0	1.0		
1.	GH1	110	99	Self-rated health	3.0	0.9		
11d.	GH2	106	95	My health is excellent	2.7	1.2		
11b.	GH3	107	96	As healthy as others	2.5	1.2		
11a.	GH4	107	96	Get sick easier than others	4.3	0.9		
11c.	GH5	106	95	Health will worsen	3.2	1.3		
9a.	VT1	107	96	Full of pep	3.6	1.2		
9e.	VT2	102	92	Have a lot of energy	3.5	1.2		
9g.	VT3	107	96	Feel worn out	4.2	1.2		
9i.	VT4	110	99	Feel tired	3.7	1.2		1
10.	SF1	110	99	Often interferes social activities	4.1	1.0		
6.	SF2	109	98	Extent interferes social activities	1.9	1.0	1	
5a.	RE1	107	96	Reduce time doing activities			26	74
5b.	RE2	109	98	Accomplished less			43	57
5c.	RE3	106	95	Not as careful			29	71
9b.	MH1	107	96	Been a nervous person	4.9	1.2		1
9c.	MH3	108	97	So down in dumps nothing helps	5.3	0.9		
9d.	MH5	107	96	Felt calm & peaceful	3.4	1.2		
9f.	MH2	107	96	Felt downhearted/blue	4.8	1.0		1
9h.	MH4	108	97	Been a happy person	2.6	0.9		
2.	TRA N	110	99	Compare health 1-yr ago	3.1	0.7		

All % values rounded off to full percent; all means and SD were rounded off to first decimal.

Table 18.

B.C. Caregiver Health - SF-36 Summary Means (N = 111)

		Mean	SD
Physical function	PF	77	21
Role physical	RP	57	39
Bodily Pain	BP	66	25
General Health	GH	64	19
Vitality	VT	54	19
Social Function	SF	77	21
Role Emotional	RE	67	39
Mental Health	MH	72	14

Summary scores = raw scored that were recoded, scaled and transformed using SPSS. Missing values replaced with mean.

Scale from 0-100, higher value means better health status.

# Table 19.

B.C. Caregiver Domain Satisfaction (N = 111)

N	%	Domains of Satisfaction (# on questionnaire)	Mean	SD
107	96	Your home (#1)	5.9	1.3
108	97	Your neighborhood as a place to live (#2)	6.1	1.4
109	98	Your family relations, generally (#3)	5.7	1.5
101	91	Your living partner (eg spouse) (#4)	6.0	1.4
32	29	Your job (#6)	5.5	1.5
106	95	Your friendships (#7)	5.8	1.4
109	98	Your health (#8)	5.1	1.7
87	78	Your religion or spiritual fulfillment (#9)	5.6	1.4
107	96	Your financial security (#11)	5.5	1.6
105	95	Your recreation activities (#12)	4.6	1.8
108	97	Your self esteem (#13)	5.3	1.5
108	97	Your overall standard of living (#14)	5.8	1.4

Satisfaction: scale from 1-7, where 1 is very dissatisfied, 7 is very satisfied.

# Table 20.

B.C. Caregiver Quality of Life (N = 111)

N	%	Domains of Quality of Life (# on questionnaire)	Mean	SD	
108	97	Satisfaction with life as a whole (#5)	5.6	1.4	
107	96	Satisfaction with overall quality of life (#10)	5.6	1.3	
107	96	Happiness with life as a whole	5.3	1.4	
Set: 6		and in 1.7 where 1 is some dispetiation 7 is some and	infied		

Satisfaction: scale is 1-7, where 1 is very dissatisfied, 7 is very satisfied. Happiness: scale is 1-7, where 1 is very unhappy, 7 is very happy.

### Stroke Survivor-Caregiver Dyads

Stroke survivor-caregiver dyads were pairs of questionnaires matched by questionnaire numbers and congruent demographic data. This data-set was composed of 103 stroke survivor questionnaires and 103 matching caregiver questionnaires for a total of 206 questionnaires.

Descriptive statistics were not performed on the stroke survivor-caregiver data-set because the size of the data-sets were similar (103 compared to 111 caregivers and 103 compared to 121 stroke survivors). The likelihood of 8 or 18 respondents changing the results was considered too small.

Although the numerical differences between the three data-sets were considered small, each was used for to analyze a different group. The stroke survivor-caregiver dyad data-set (N=103 pairs) was used for stroke survivor-caregiver analysis to ensure a 100% match between each stroke survivor and their personal caregiver. The stroke survivor data-set (N=121) was used for stroke survivor only analysis as the group size was larger than the dyad data-set and all subjects met the criteria to be a stroke survivor. The caregiver data-set (N=111) was used for caregiver only analysis again because this group was larger than the dyad data-set.

### **CHAPTER IV**

# **COMPARISONS & ANALYSIS**

The second objective of this study was to compare B.C. stroke survivor and B.C. caregiver descriptive results to literature and analyze relationships among the variables.

### **Interesting Comparisons**

# **Caregiver Burden Compared to Literature**

Table 21 shows the Caregiver Burden Scale (CBS) mean scores for caregivers in the current B.C. study and for caregivers in a Swedish study done by Elmstahl, Malmberg and Annerstedt (1996). These groups were different in several ways. In the B.C. study there were 111 caregivers and in the Swedish study there were 35 caregivers. In the B.C. study the all caregivers were in one group and 87% were spouses to the stroke survivor. In the Swedish study there was a group of 19 spouse caregivers and a group of 16 sibling/other caregivers. In the B.C. study, caregivers came from throughout British Columbia (rural and urban), while in the Swedish study they came from one large city. In the B.C. study, stroke survivors were 6-years post-stroke, while in the Swedish study they were 3-years post-stroke. Demographic details such as age were not reported in the Swedish study. To the writer's knowledge, the Swedish study was the only published study using the Caregiver Burden Scale for caregivers of stroke survivors.

The CBS is scored from 1-4 where higher scores means higher burden. For B.C. caregivers, the mean score for the total CBS was 2.2 and for Swedish spouse caregivers it was 2.0. On the five CBS indexes, the general strain score for B.C. caregivers was 2.4

compared to 2.2 for Swedish spouse caregivers, isolation was 2.3 compared to 2.1, disappointment was 2.2 compared to 2.1, and emotional involvement was 1.8 compared to 1.7. Environment burden score was the same for both studies at 1.7. For B.C. caregivers, the mean scores for total burden, and on each of the five indices, were higher than the Swedish sibling/other caregivers, which could indicate that B.C. caregivers had higher burden. However, without raw data, it was impossible to measure the statistical significance of the differences. As well, because the group sizes were so different (111 and 19) the statistical analysis would be uncertain. If B.C. caregivers do have greater burden than Swedish caregivers, it may be related to being a caregiver for a longer period of time or it could be related to how people in different parts of the world perceive burden.

### Table 21.

B.C. Caregiver Burden Com	pared to	Literature
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Caregiver Burden Scale	a) Caregiver data- set (N=111)	b) Spouse Caregivers (N=19)	c) Children/ siblings (N=16)
	Means	Means	Means
Total Burden	2.2	2.0	1.7
General Strain	2.4	2.2	1.9
Isolation	2.3	2.1	1.4
Disappointment	2.2	2.1	1.6
Emotional Involvement	1.8	1.7	1.6
Environment	1.7	1.7	1.7

Means were rounded off to the first decimal point.

Items were scored from 1 to 4 (not at all, seldom, sometimes and often). A low score indicates low burden and a high score indicates high burden.

a) B.C. caregiver data-set (N=111)

b) Elmstahl, Malmberg & Annerstedt, 1996 study, (N=19), Malmo University Hospital, Sweden. These 19 caregivers were spouses of the stroke survivors.

c) Elmstahl, Malmberg & Annerstedt, 1996 study, (N=16), Malmo University Hospital, Sweden. These 16 caregivers were children or siblings of the stroke survivors.

b) & c) Stroke survivors had their stroke 3 years prior to the time the study was done.

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# Stroke Survivor Health Compared to the Literature

Table 22 shows self-reported health status for B.C. stroke survivors (column a), New Zealand stroke survivors (column b), controls matched for the New Zealand stroke survivors (column c), Australian stroke survivor studies 1-year post stroke (columns d), Australian stroke survivors who had home-based rehabilitation who were studied 6-months post-stroke (column e), Australian stroke survivors who had conventional rehabilitation who were studied 6-months post-stroke (column f), a sample of the general population from Prince George, 1998 values (column g), and people with serious medical illnesses (advanced or complicated chronic medical conditions whereby 35% had advanced coronary heart disease, 21% had hypertension, and 64% had diabetes) conducted in the USA (column h). Stroke survivors in the B.C. study (column a) and those in the New Zealand study (column b) were similar in time since stroke, mean age, and age ranges.

Self-reported health status was summarized by eight SF-36 scales scored from 0-100 whereby a higher score means better health status. The B.C. stroke survivors had poorer self-reported health on all eight SF-36 scales (except for SF-36 bodily pain) than each comparison group shown in Table 22. It would be reasonable to expect that stroke survivors would have poorer self-reported health status than the general population. This expectation was found; B.C. stroke survivors had considerably lower mean scores on 7 out of 8 SF-36 subscales than the general population. It would be reasonable to expect that B.C. stroke survivors would have similar self-reported health status to a comparable stroke survivor group. This expectation was not found; B.C. stroke survivors had considerably lower mean scores on all eight SF-36 scores than the New Zealand

stroke survivor group. More research would be needed to understand the poor selfreported health status of the B.C. stroke survivors.

The following describes the self-reported health status for B.C. stroke survivors and other groups. On the SF-36 physical functioning scale, the mean score for B.C. stroke survivors was 33, for New Zealand stroke survivors, the best comparison group to B.C. stroke survivors, it was 48, for the controls in the New Zealand study it was 70, for Australian stroke survivors who were 1-year post-stroke it was 48, for Australian stroke survivors who had home-based rehabilitation it was 41, for Australian stroke survivors who had conventional rehabilitation it was 43, for the general population it was 87, and for people with serious medical illnesses it was 57. The B.C. stroke survivors' SF-36 physical functioning scores were skewed toward the low end of the scale and were considerably lower than all other groups. To summarize, B.C. stroke survivors have considerable limitations in performing all physical activities including bathing or dressing due to health (Table 1) and these problems are considerably worse than in other groups.

It is interesting to note that the changes in mean SF-36 physical functioning scores for stroke survivors over time. Stroke survivors 6-months post-stroke had mean physical functioning scores of 41 and 43, at 1-year post-stroke it improved to 48, and at 6-years post-stroke in the New Zealand group it was maintained at 48 whereas in the B.C. group it was 33. It appears that stroke survivors, except for those in B.C., improve in physical functioning over time as was seen in studies done 5-,14- and 20-years following a stroke.

On the SF-36 role physical scale, the mean score for B.C. stroke survivors was 30, for New Zealand stroke survivors, the best comparison group to B.C. stroke survivors, it was 65, for the controls in the New Zealand stroke study it was 78, for Australian stroke survivors 1-year post-stroke it was 76, for stroke survivor who had home-based rehabilitation it was 71, for stroke survivor who had conventional rehabilitation it was 77, for the general population study it was 82, and for people with serious medical illnesses it was 44. The B.C. stroke survivors' SF-36 role physical score was their lowest SF-36 score, was skewed toward the low end of the scale, and was considerably lower than all other groups. To summarize, B.C. stroke survivors have considerable problems with their work or other daily activities as a result of physical health (Table 1) and these problems are much worse than in other groups.

On the SF-36 bodily pain scale, B.C. stroke survivors had a mean score of 62. Five groups had higher mean SF-36 bodily pain scores (less bodily pain) than B.C. stroke survivors. The mean SF-36 bodily pain score for New Zealand stroke survivors was 72, for controls in the New Zealand stroke study it was 76, for Australian stroke survivors 1-year post-stroke it was 76, for Australian stroke survivors who had conventional rehabilitation it was 70, and for people with serious medical illnesses it was 65. Two groups had mean SF-36 bodily pain scores that were essentially the same as B.C. stroke survivors. The mean SF-36 bodily pain score for Australian stroke survivors who had home-based rehabilitation was 61 and surprisingly, for the general population in Prince George study it was 61. While it could be expected that two stroke survivor groups could have similar low bodily pain scores, this would not be expected for the general

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population group. Interestingly, the mean SF-36 bodily pain score for the general population in Prince George was lower than other general population studies. The mean SF-36 bodily pain score in a USA study was 75, in a UK study it was 84, in a Dutch study it was 82, in Aberdeen it was 77, and in Sweden it was 75 (Michalos, Zumbo & Hubley, 1999). To summarize, B.C. stroke survivors have very severe and extremely limiting pain (Table 1) and this is more than in most other groups.

On the SF-36 general health scale, B.C. stroke survivors had a mean score of 55, which was lower (poorer health) than all comparison groups. The mean SF-36 general health score for New Zealand controls was 76, for Australian stroke survivors 1-year post stroke it was 64, for Australian stroke survivors who had home-based rehabilitation it was 62, for Australian stroke survivors who had conventional rehabilitation it was 67, for the general population it was 74, and for people with serious medical illnesses it was 67. To summarize, B.C. stroke survivors evaluate their personal health as poor and believe their personal health will get worse (Table 1) and poorer general health than all other groups.

On the SF-36 vitality scale, B.C. stroke survivors mean score was 44, which was lower (less vitality) than all comparison groups. The mean SF-36 vitality score for the New Zealand stroke survivors was 47, for controls for the New Zealand stroke study it was 62, for Australian stroke survivors 1-year post-stroke it was 56, for stroke survivors who had home-based rehabilitation it was 54, for stroke survivors who had conventional rehabilitation it was 56, f, for the general population it was 58, and for people with

serious medical illnesses it was 48. These results indicate that B.C. stroke survivors feel tired and worn our all the time (Table 1) and that they have less vitality than other groups.

On the SF-36 social function scale, B.C. stroke survivors had a mean score of 64, which was lower (decreased social function) than all comparison groups. The mean SF-36 social function score for the New Zealand stroke survivors was 67, for controls in the New Zealand study it was 86, for Australian stroke survivors 1-year post-stroke it was 86, for stroke survivor who had home-based rehabilitation it was 75, for stroke survivor who had conventional rehabilitation it was 83, for the general population in Prince George it was 84, and for people with serious medical illnesses it was 80. These findings indicate that B.C. stroke survivors experience extreme and frequent interference with normal social activities due to their physical or emotional problems (Table 1) and that their social function is lower than other groups.

On the SF-36 role emotion scale, B.C. stroke survivors had a mean score of 53, which was lower (impaired role emotion) than all comparison groups. The mean SF-36 role emotion score for the New Zealand stroke survivors was 85, for controls in the New Zealand study it was 93, for Australian stroke survivors 1-year post-stroke it was 83, for stroke survivors who had home-based rehabilitation it was 93, for stroke survivors who had conventional rehabilitation it was 93, for the general population in Prince George it was 81, and for people with serious medical illnesses it was 76. These results show that B.C. stroke survivors experience problems with all daily activities as a result of emotional problems (Table 1) and that these problems are worse than in other groups.

On the SF-36 mental health scale, B.C. stroke survivors had a mean score of 69, which was lower (reduced mental health) than all comparison groups. The mean SF-36 mental health score for the New Zealand stroke survivors was 82, for controls for the New Zealand stroke study it was 85, for Australian stroke survivors 1-year post-stroke it was 77, for stroke survivor who had home-based rehabilitation it was 81, for stroke survivor who had conventional rehabilitation it was 83, for the general population in Prince George it was 75, and for people with serious medical illnesses it was 71. When the B.C. stroke survivors' mean SF-36 mental health score is compared to other studies, it is their lowest score. The B.C. stroke survivors feel nervous and depressed all of the time (Table 1). However, when the B.C. stroke survivors' mean SF-36 mental health score is compared to their other SF-36 scores, it is their highest score. The B.C. stroke survivors feel peaceful, happy and calm all of the time (Table 1). So what is the mental health description of B.C. stroke survivors? To answer this question more research is needed. An interesting observation was that all things being equal, mean SF-36 mental health scores decrease (worsen) over time for stroke survivors. The mean SF-36 mental health scores at 6-months post-stroke were 81 and 83, at 1 year post-stroke it was 77, and at 6-years post-stroke for the B.C. stroke survivors it was 69. (The exception to this observation was the New Zealand stroke survivor group who had an exceptionally high mean SF-36 mental health score of 82.) One explanation for high mental health scores soon after a traumatic event, such as a stroke, is that people are happy to be alive. The steady decrease in mean mental health scores over time may reflect limitations from the stroke and less hope for improvement.

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B.C. Stroke Survivor Health Compared to Literature

	a) B.C. Stroke Survivor data-set	b) Stroke Survivor, New Zealand	c) Controls for study b)	d) Stroke survivor, Australia	e) Stroke survivor, Home- based rehab, Australia	f) Stroke survivor Conven- tional rehab, Australia	g) General Popula- tion, Prince George	h) Serious Medical Illness, USA
Stroke survivor	Yes	Yes	No	Yes	Yes	Yes	No	No
Time since stroke	6 yrs post stroke	6 yrs post stroke		l yr post stroke	6 mo post- stroke	6 mo post- stroke	NA	NA
Age -range -mean (x)	30-93 yrs x = 70 yrs	25-96 yrs x = 71 yrs	Matched for study e) for age & sex	36-92 yrs x = 72 yrs	66-78 yrs x = 72 yrs	66-78 yrs x = 72 yrs	18-92 yrs x = 46 yrs	x = 61 yrs
N	N =121	N=639	N=310	N=90	N=42	N=41	N=709	N=144
SF-36	Means	Means	Means	Means	Means	Means	Means	Means
PF	33	48	70	48	41	43	87	57
RP	30	65	78	76	71	77	82	44
BP	62	72	76	76	61	70	61	65
GH	55	60	76	64	62	67	74	67
VT	44	47	62	56	54	56	58	48
SF	64	67	86	86	75	83	84	80
RE	53	85	93	83	93	93	81	76
MH	69	82	85	77	81	83	75	78

Means rounded off to a full integer.

A higher mean score means better health status with 100 being the highest possible.

a) Current Study, British Columbia, 2001

b) Hackett, Duncan, Anderson, Broad & Bonita, 2000

c) Hackett, Duncan, Anderson, Broad & Bonita, 2000. Age- and gender-matched controls for e)

d) Anderson, Laubscher & Burns, 1999

e) Anderson, Rubenach, Mhurchu, Clark, Spencer & Winsor, 2000

f) Anderson, Rubenach, Mhurchu, Clark, Spencer & Winsor, 2000

g) Michalos, Zumbo & Hubley, 2000

h) McHorney, Ware & Raczek, 1993

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# **Caregiver Health Compared to Literature**

Table 23 shows the SF-36 mean scores for B.C. caregivers (column a), caregivers of stroke survivors treated with home-based rehabilitation who were studied 6-months post-stroke (column b), caregivers of stroke survivors treated with conventional rehabilitation who were studied 6-months post-stroke (column c), a sample of the general population (column d), and people with minor medical conditions (uncomplicated chronic medical conditions) (column e). Anderson, Rubenach, Mhurchu, Clark, Spencer, and Winsor (2000) did not report caregiver demographics.

Generally speaking, B.C. caregivers had similar self-reported health scores when compared to the two other caregiver groups. Generally speaking, B.C. caregivers had lower mean scores on all SF-36 scales (except bodily pain) when compared to the general population and people with minor medical conditions.

On the SF- 36 physical functioning scale, B.C. caregivers had a mean score of 77. The mean SF-36 physical functioning score for caregivers of stroke survivors who received home-based rehabilitation was 76, for caregivers of stroke survivors who received conventional rehabilitation it was 73, for people with minor medical conditions it was 81, and for the general population it was 87. These results indicate that B.C. caregivers, like other caregivers, are limited in performing physical activities, including bathing or dressing, due to poor health (Table 1) and they are more limited than the general population and those with minor medical conditions.

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On the SF-36 role physical scale, B.C. caregivers had a mean score of 57, which was lower (impaired role physical) than other groups. The mean SF-36 role physical score for caregivers of stroke survivors who received home-based rehabilitation was 74, for caregivers of stroke survivors who had conventional rehabilitation it was 61, for the general population it was 82, and for those with minor medical conditions it was 70. These results indicate that B.C. caregivers have problems at work or with everyday activities as a result of their poor physical health (Table 1) and that they had more problems than each comparison group (with caregivers of stroke survivors who received conventional rehabilitation as possible exception as their mean scores were similar).

On the SF-36 bodily pain scale, B.C. caregivers had a mean score of 66. The mean SF-36 bodily pain score for caregivers of stroke survivors who received home-based rehabilitation was 67, for caregivers of stroke survivors who received conventional rehabilitation it was 57, for the general population it was 61, and for people with minor medical conditions it was 76. These results indicate that B.C. caregivers have similar bodily pain to caregivers of stroke survivors who received home-based rehabilitation, have less bodily pain than caregivers of stroke survivors who received conventional rehabilitation and the general population, and more bodily pain than for people with minor medical conditions.

On the SF-36 general health scale, B.C. caregivers had a mean score of 64. The mean SF-36 general health score for caregivers of stroke survivors who received conventional rehabilitation was 64, for the general population it was 74, for people with minor medical
conditions it was 67, and for caregivers of stroke survivors who received home-based rehabilitation it was 68. These results indicate that B.C. caregivers evaluate their health as poor and believe it will get worse (Table 1) and do so more than the other groups.

On SF-36 vitality scale, B.C. caregivers had a mean vitality score of 54. The mean SF-36 vitality score for caregivers of stroke survivors who received home-based rehabilitation was 55, for the general population it was 58, for people with minor medical conditions it was 62, and for caregivers of stroke survivors who received conventional rehabilitation it was 58. These results indicate that B.C. caregivers, like caregivers of stroke survivors who received home-based rehabilitation, feel tired and worn out most of the time (Table 1) and that they feel more fatigue than the general population, people with minor medical conditions.

On SF-36 social functioning scale, B.C. caregivers had a mean score of 77. The mean SF-36 social functioning score for caregivers of stroke survivors who received home-based rehabilitation was 75, for caregivers of stroke survivors who received conventional rehabilitation it was 80, for the general population it was 84, and for people with minor medical conditions it was 91. These results indicate that B.C. caregivers, like caregivers of stroke survivors who received home-based rehabilitation, experience extreme and frequent interference with normal social activities due to poor physical or emotional health (Table 1) and that they have worse social functioning than caregivers of stroke survivors who received conventional rehabilitation, the general population, and people with minor medical conditions.

On the SF-36 role emotional scale, B.C. caregivers had a mean score of 67, which was lower than all comparative groups. The mean SF-36 role emotion score for the general population was 81, for people with minor medical conditions it was 84, for caregivers of stroke survivors who received home-based rehabilitation it was 80, and for caregivers of stroke survivors who received conventional rehabilitation it was 73. These results indicate that B.C. caregivers have problems with daily activities as a result of their poor emotional health (Table 1) and that their problems are greater those in the other groups.

On the SF-36 mental health scale, B.C. caregivers had a mean score of 73. The mean SF-36 mental health score for caregivers of stroke survivors who received home-based rehabilitation was 70, for the general population it was 75, for people with minor medical conditions it was 82, and for caregivers of stroke survivors who received conventional rehabilitation it was 82. These results indicate that B.C. caregivers have similar mental health to caregivers of stroke survivors who received home-based rehabilitation and the general population, but feel more nervous and depressed all of the time (Table 1) than people with minor medical conditions and caregivers of stroke survivors who received conventional rehabilitation.

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B.C. Caregiver Health Compared to Literature

	a) B.C. Caregivers	b) Caregivers, Australia	c) Caregivers, Australia	d) General Population, Prince George	e) Minor Medical Conditions, USA
Caregiver	Of a stroke survivor. 6 years post- stroke.	Of a stroke survivor who had home- based rehabilitation. 6 months post- stroke.	Of a stroke survivor who had conventional rehabilitation. 6 months post- stroke	No	No
Age -range -mean (x)	24-84 yrs x = 65 yrs	Not reported	Not reported	18-92 yrs x = 46 yrs	x = 57 yrs
N	N=111	N=24	N=25	N=709	N=638
SF-36	Means	Means	Means	Means	Means
PF	77	76	73	87	81
RP	57	74	61	82	70
BP	66	67	57	61	76
GH	64	68	64	74	67
VT	54	55	58	58	62
SF	77	75	80	84	91
RE	67	80	73	81	84
MH	73	70	82	75	82

Means rounded off to a full integer.

A higher score/mean infers better health status with 100 being the highest possible.

a) Current Study, British Columbia, 2001

b) Anderson, Rubenach, Mhurchu, Clark, Spencer & Winsor, 2000

c) Anderson, Rubenach, Mhurchu, Clark, Spencer & Winsor, 2000

d) Michalos, Zumbo & Hubley, 2000

e) Patients with uncomplicated chronic medical conditions, McHorney, Ware & Raczek, 1993

# **Domain Satisfaction Compared to Literature**

Table 24 shows mean domain satisfaction scores for three groups: stroke survivors in the current study, caregivers in the current study, and a sample of the general population living in Prince George in 1998. Domain satisfaction items were measured on a 7-point scale where higher scores indicate more satisfaction. According to Michalos (personal communication, February 2002), a difference of 0.3 or more in mean scores on these domain satisfaction items is usually statistically significant.

Eleven mean domain satisfaction scores for B.C. stroke survivors (column a) were compared to the general population (column c). B.C. stroke survivors had significantly higher mean scores than the general population on three items: satisfaction with their living partner (6.4 for stroke survivors and 5.9 for the general population), satisfaction with religion or spiritual fulfillment (5.5 for stroke survivors and 5.0 for the general population), and satisfaction with financial security (5.4 for stroke survivors and 4.3 for the general population). These results indicate that B.C. stroke survivors, compared to the general population, are more satisfied with their partner or spouse. One reason for this might be that stroke survivors are very indebted and appreciative of their partner or spouse. The B.C. stroke survivors, compared to the general population, are more satisfied with their religion/spiritual fulfillment. It might be that stroke survivors turn to God or spiritual beliefs, to try to understand why they had a stroke, why they survived their stroke, or both. The B.C. stroke survivors are more satisfied with their financial affairs than the general population. This could reveal that the stroke event may result in the stroke survivor's financial affairs being attended to or managed in a manner that is satisfying.

In contrast, B.C. stroke survivors had lower mean scores than the general population on two of the 11 satisfaction items: satisfaction with health (4.4 for stroke survivor and 5.3 for the general population) and satisfaction with recreation activities (4.4 for stroke survivors and 4.7 for the general population). These results indicate that B.C. stroke survivors were less satisfied with their health compared to the general population. This result is reasonable considering how poor their self-reported health was on the SF-36. As well, B.C. stroke survivor were less satisfied with their recreation than the general population. This result is also reasonable considering their limitations from stroke effects and health.

Eleven mean domain satisfaction scores for B.C. caregivers (column b) were compared to the general population (column c). B.C. caregivers had higher mean scores on two items: satisfaction with religion or spiritual fulfillment (5.6 for caregivers and 5.0 for general population) and satisfaction with financial security (5.5 for caregivers and 4.3 for general population). The B.C. caregivers, compared to the general population, had greater satisfaction with their religion/spiritual fulfillment. The B.C. caregivers may turn to God or spiritual beliefs to try to understand why their spouse had and survived a stroke, why they were the ones that were spared, or both. The B.C. caregivers, compared to the general population, have greater satisfaction with their finance security. This could reveal that the stroke event may result in the caregiver's financial affairs being attended to or managed in a manner that is satisfying.

Eleven mean domain satisfaction scores for B.C. stroke survivors (column a) and B.C. caregivers (column b) were compared. Stroke survivors had higher mean scores on only one domain satisfaction item, namely satisfaction with partner/spouse (6.4 for stroke survivor and 6.0 for caregivers). This result may indicate that stroke survivors have high satisfaction for what their spouse does to help them and relatively speaking may indicate that caregivers have lower satisfaction with their partner likely due to some caregiver burden. In contrast, stroke survivors had lower mean scores on three items: satisfaction with friendships (5.4 for stroke survivors and 5.8 for caregivers), satisfaction with health (4.4 for stroke survivors and 5.1 for caregivers), and satisfaction with self-esteem (5.0 for stroke survivors and 5.3 for caregivers). These results are reasonable and could be expected. Stroke survivors, compared to caregivers, were less satisfied with their friendships; this most likely was due to losing friends and having difficulty meeting new ones. Stroke survivors, compared to caregivers, were less satisfied with their health; this most likely was due to their poor self-reported health status. Stroke survivors, compared to caregivers, had lower self-esteem; this could be due to their reduced or changed roles, as seen by their low SF-36 role physical and role emotion mean scores.

# **Quality of Life Compared to Literature**

Table 25 shows mean overall quality of life scores for B.C. stroke survivors, B.C. caregivers, and the general population. Overall quality of life was measured with three items using a 7-point scale whereby higher scores indicate better quality of life.

The B.C. stroke survivors, compared to the general population, had lower mean scores on all three measures of overall quality of life: satisfaction with life as a whole (5.2 for stroke survivors and 5.5 for the general population), satisfaction with overall quality of life (4.8 for stroke survivors and 5.5 for the general population), and happiness with life as a whole (5.1 for stroke survivors and 5.6 for the general population). The B.C. caregivers, compared to the general population, had lower mean scores on one measure of overall quality of life: happiness with life as a whole (5.3 for caregivers and 5.6 for the general population). The B.C. caregivers, so one measure of overall quality of life: happiness with life as a whole (5.3 for caregivers and 5.6 for the general population). The B.C. caregivers, had lower mean scores on two dimensions of quality of life: satisfaction with life as a whole (5.2 for stroke survivors and 5.6 for caregivers) and satisfaction with overall quality of life (4.8 for stroke survivors and 5.6 for caregivers).

## Table 24.

Domain Satisfaction Comparisons: B.C. Stroke Survivor, B.C. Caregiver, Literature

Domain Satisfaction Means	a) B.C Stroke Survivor data-set N=121	b) B.C Caregiver data-set N=111	c) General population, Prince George N=709
Your home	5.9	5.9	5.8
Your neighborhood as a place to live	6.0	6.1	5.9
Your family relations, generally	5.9	5.7	5.7
Your living partner (eg spouse)	6.4	6.0	5.9
Your job	4.9	5.5	5.2
Your friendships	5.4	5.8	5.6
Your health	4.4	5.1	5.3
Your religion or spiritual fulfillment	5.5	5.6	5.0
Your financial security	5.4	5.5	4.3
Your recreation activities	4.4	4.6	4.7
Your self esteem	5.0	5.3	5.2
Your overall standard of living	5.6	5.8	Not reported

Scale between 1 = very dissatisfied and 7 = very satisfied.

Higher value means greater satisfaction.

a) & b) Current Study, British Columbia, 2001

c) Michalos, Zumbo & Hubley, 2000. Used 1998 values.

#### Table 25.

Quality of Life Comparisons: B.C. Stroke Survivor, B.C. Caregiver, and General Population

Quality of Life Means	a) B.C. Stroke Survivor data-set N=121	b) B.C. Caregiver data-set N=111	c) General population, Prince George N=709
Satisfaction with life as a whole	5.2	5.6	5.5
Satisfaction with overall quality of life	4.8	5.6	5.5
Happiness with life as a whole	5.1	5.3	5.6

Scale between 1 = very dissatisfied/unhappy and 7 = very satisfied/happy.

Higher value means greater satisfaction.

a) & b) Current Study, British Columbia, 2001

c) Michalos, Zumbo & Hubley, 2000. 1998 values were used.

# **Bivariate Analysis – Correlations**

In this study six sets of correlations were examined. First, stroke survivor function was correlated with stroke survivor variables. Second, caregiver burden was correlated with caregiver variables. Third, stroke survivor function was correlated with caregiver variables. Fourth, caregiver burden was correlated with stroke survivor variables. Fifth, stroke survivor quality of life was correlated with stroke survivor domain satisfaction. And sixth, caregiver quality of life was correlated with caregiver domain satisfaction.

### 1. Stroke survivor function correlated with stroke survivor variables

Table 26 shows the mean stroke survivor FEFA total score correlated with mean stroke survivor self-reported health scores (8 SF-36 health scores), mean stroke survivor domain satisfaction scores (11 domains), and mean stroke survivor overall quality of life scores (3 measures of overall quality of life).

### Stroke survivor function and stroke survivor health

The mean stroke survivor FEFA total score significantly and negatively correlated with mean stroke survivor SF-36 physical functioning scores (r = -.53, p = 0.001), SF-36 general health (r = -.20, p = 0.04) and SF-36 social function (r = -.25, p = 0.01). The negative direction indicates for example, that a low FEFA score (independent function) correlated with high SF-36 physical functioning score (good physical functioning), and a low high FEFA score (dependence) correlated with low SF36 physical functioning scores (poor physical functioning). This is the direction that would be expected.

The FEFA and PF both measure some sort of physical functioning. The FEFA measures for example mobility, toileting, meals preparation, dressing, bathing, hand function, and using a telephone. The SF-36 physical functioning subscale measures vigorous activities, moderate activities, climbing stairs, walking, bending/kneeling/stooping, and bathing/dressing. Since both FEFA and PF measure some sort of physical functioning there is not much point in thinking of either variable as independent or dependent. However, it is reasonable to suppose that the FEFA score (independent variable) would be a predictor of the SF-36 general health (dependent variable). This would hold true for FEFA (independent variable) and SF-36 social functioning (dependent variable).

The percent of variation in one of the correlates attributable to the other correlate can be determined by squaring the correlation coefficients. In other words, it shows the percentage of shared variance between two variables. For example, the mean stroke survivor FEFA total score and mean stroke survivor SF-36 physical functioning score, which have a correlation of .53, share 28% of their variance. The mean stroke survivor FEFA total score and mean stroke survivor SF-36 general health score, with a correlation of -.20, share 4% of their variance. The mean stroke survivor SF-36 social functioning score, with a correlation of -.20, share 4% as two examples are statistically significant, but are very small.

# Stroke survivor function and stroke survivor domain satisfaction

The mean stroke survivor FEFA total score was correlated with the 11 mean domain satisfaction scores. Surprisingly, only one statistically significant correlation was found,

whereby the mean stroke survivor FEFA total score was correlated with the mean stroke survivor satisfaction with health (r = -.22, p = 0.03, n = 99). Although this correlation is significant, it is small, whereby only 5% of their variance is shared.

As more correlations were expected to be significant, data were double-checked, all correlations were re-done, and scatter plots were re-examined. Distributions of points were acceptable and scatter plots showed points distributed evenly throughout all four quadrants of the graph; no plot had curvilinear distributions. However, inspection of a bar graph of FEFA scores showed the results were skewed at the independent end of the scale with 90% of scores below 15 points. The low level of variance in FEFA scores may explain the low level of correlations found. In other words, the FEFA questionnaire had a range restriction effect where most of the scores bunched up at one end, in this case towards the independence end of the scale. Interestingly, a stroke survivor commented that "...I found your questionnaire, especially the earlier questions (sic, which would be the FEFA), to be geared to people who would be more commonly found living in care homes NOT in the community..." (Appendix G).

# Stroke survivor function and stroke survivor quality of life

The mean stroke survivor FEFA total score significantly and negatively correlated with the mean score for satisfaction with overall quality of life (r = -.22, p = 0.02). This inverse relationship would be the expected direction. For example, if all other things are equal, the greater one's functional independence, the greater one's satisfaction with the overall quality of life. Despite being statistically significant, only 5% of the CBS mean

scores (or caregiver burden) can be attributed to FEFA mean scores (or stroke survivor function).

### 2. Caregiver burden correlated with caregiver variables

Table 26 shows the mean Caregiver Burden Scale (CBS) total score, correlated with mean caregiver self-reported health scores (8 SF-36), mean domain satisfaction scores (11 domains), and overall quality of life scores (3 measures of overall quality of life).

# Caregiver burden and caregiver health

The mean Caregiver Burden Scale (CBS) total score, significantly and negatively correlated with all 8 SF-36 health scores at a significance level of p<0.001 with at least 96 pairs. The mean CBS total score significantly correlated with mean scores for caregiver SF-36 physical function (r = -.28), role physical (-.40), body pain (-.48), general health (-.39), vitality (-.57), social function (-.55), role emotional (-.44), and mental health (-.57). The two largest correlations were between caregiver burden and vitality, which shared 33% of their variance; and between caregiver burden and mental health, which also shared 33% of their variance. These results indicate that higher caregiver burden has a negative impact on all aspects of caregiver self-reported health, but especially on vitality and mental health. Although this relationship and direction was expected, it is dramatic to see it for all 8 SF-36 health dimensions. Further, it is interesting to see that increased caregiver burden affects mental health and vitality scales, more so than some physical scales.

### Caregiver burden and caregiver domain satisfaction

The mean Caregiver Burden Scale (CBS) total score, significantly and negatively correlated with all 11 caregiver mean domain satisfaction scores at p<0.05 (or better). The inverse relationship would be expected. The mean CBS total scores correlated with the mean scores for, caregiver satisfaction with: home (r = -.23), neighborhood (-.27), family relations (-.34), partner (-.50), friendships (-.24), health (-.44), religious/spiritual (-.32), financial security (-.26), recreation activities (-.49), self esteem (-.32), and standard of living (-.30). The two largest correlations were between caregiver burden and satisfaction with partner, which shared 25% of their variance; and between caregiver burden and satisfaction between caregiver burden and satisfaction with partner is interesting given 87% of the caregivers are also the stroke survivors spouses. Thus in some cases, where caregiver spouses have high burden, they still care, but they risk satisfaction with their partner. The cost of high caregiver burden is reduced satisfaction with all satisfaction items, but especially, satisfaction with their partner, recreation, health, and family relations.

### Caregiver burden and caregiver quality of life

The mean CBS total score significantly and negatively correlated with all three caregiver quality of life measures at p<0.001. The mean CBS total score was significantly and negatively correlated with mean satisfaction with life as a whole score (r = -.39). High caregiver burden relates to low satisfaction with life as a whole, and low caregiver burden relates to high satisfaction with life as a whole. However, although the correlation was significant it is relatively small, such that only 15% of the variance in satisfaction with

life as a whole may be attributed to caregiver burden. On the upside, this leaves 85% of variance in satisfaction with life as a whole, to other variables, some of which may be enjoyment variables. The mean CBS total score was significantly and negatively correlated with satisfaction with overall quality of life (r = -.47). Thus, 22% of variance in satisfaction with overall quality of life may be attributed to caregiver burden, which leaves 88% for other variables. The mean CBS total score was significantly and negatively correlated with happiness with life as a whole (r = -.47). Thus, 22% of the variance in happiness with life as a whole may be attributed to caregiver burden, which leaves 88% for other variables. These findings indicate that although caregiver burden impacts the overall quality of life of caregivers, it is not all consuming of quality of life.

Table 26.

B.C. Stroke Survivor Function Correlated with B.C. Stroke Survivor Health, QOL and Domain Satisfaction; B.C. Caregiver Burden correlated with B.C. Caregiver Health, QOL and Domain Satisfaction

B.C. Stroke survivor function (FEFA) correlated			B.C. Caregiver burden (CBS) correlated with		
with B.C. stroke survivor variables using stroke			B.C. caregiver variables using caregiver data-		
survivor data-set ( $N = 121$ ):			set $(N = 111)$ :		
Stroke survivor health – SF36			Caregiver health – SF36		
Physical function	53** P=0.001	N=95	Physical function	28** P=0.01 N=100	
Role physical	NS		Role physical	40** P=0.00 N=104	
Body pain	NS		Body pain	48** P=0.00 N=109	
General health	20* P=0.04	N=112	General health	39** P=0.00 N=103	
Vitality	NS		Vitality	57** P=0.00 N=96	
Social function	25** P=0.01	N=115	Social function	55** P=0.00 N=109	
Role emotional	NS		Role emotional	44** P=0.00 N=105	
Mental health	NS		Mental health	57** P=0.00 N=98	
Stroke survivor doma	ain satisfaction		Caregiver domain satisfaction		
Home	NS		Home	23* P=0.02 N=107	
Neighbourhood	NS		Neighbourhood	27** P=0.01 N=108	
Family relations	NS		Family relations	34** P=0.00 N=109	
Living partner	NS		Living partner	50** P=0.00 N=101	
Friendships	NS		Friendships	24* P=0.01 N=106	
Health	22* P=0.03	N=99	Health	44** P=0.00 N=109	
Religious/spiritual	NS		Religious/spiritual	32** P=0.00 N=87	
Financial security	NS	- 0	Financial security	26** P=0.01 N=107	
<b>Recreation</b> activities	NS		Recreation activities	49** P=0.00 N=105	
Self esteem	NS		Self esteem	32** P=0.00 N=108	
Standard of living	NS		Standard of living	30** P=0.00 N=108	
Stroke survivor quality of life Ca			Caregiver quality of 1	ife	
Life as a whole	NS		Life as a whole	39** P=0.00 N=108	
Overall QOL	28** P=0.006	N=97	Overall QOL	47** P=0.00 N=107	
Happiness	NS		Happiness	47** P=0.00 N=107	

NS = not significant at 0.05

\* = significant at <0.05

\*\* = significant at <0.001

### 3. Stroke survivor function correlated with caregiver variables

The mean stroke survivor FEFA total score was correlated with mean caregiver selfreported health scores (8 SF-36 scales), mean caregiver domain satisfaction scores (11 items), and mean caregiver overall quality of life scores (3 measures of overall quality of life). There were no statistically significant relationships were found among these correlations. This result seems surprising, some relationships were expected between stroke survivor function and these caregiver variables. For example, it was expected that low stroke survivor FEFA score (independence) would be related to high caregiver overall quality of life, but this was not found.

#### 4. Caregiver burden correlated with stroke survivor variables

### Caregiver burden and stroke survivor function

Table 27 shows statistically significant relationships among caregiver burden and stroke survivor function. The mean CBS total score was significantly and positively correlated with the mean stroke survivor FEFA total score (r = .23, P = .02). Thus high a mean FEFA score (dependence) correlates with a high CBS score (high burden), and low FEFA score (independence) correlates with a low CBS score (low burden). Although the correlation does not indicate causal direction, it would be expected that stroke survivor function would contribute to caregiver burden, and not the reverse. Although the relationship was statistically significant, it is small. Only 5% of the variance in caregiver burden could be attributed to stroke survivor function.

### Caregiver burden and stroke survivor health

Table 27 shows only two statistically significant relationships among caregiver burden and stroke survivor health. The mean CBS total score was significantly and negatively correlated with the mean stroke survivor SF-36 bodily pain score (r = -.30, P = 0.002). The correlation does not indicate causal direction, however it is more likely that stroke survivor pain would contribute to caregiver burden, rather than the reverse. Although the correlation is significant, it was small, such that only 9% of the variance in mean CBS score may be attributed to mean stroke survivor SF-36 bodily pain score. The mean CBS total score was also significantly and negatively correlated with the mean stroke survivor SF-36 general health score (r = -.21, P = 0.04). It is more likely that stroke survivor general health would affect caregiver burden, rather than the reverse. Although the correlation is significant, it is small, such that only 4% of the variance in mean CBS score may be attributed to mean stroke survivor SF-36 general health would affect caregiver burden, rather than the reverse. Although the correlation is significant, it is small, such that only 4% of the variance in mean CBS score may be attributed to mean stroke survivor SF-36 general health score.

#### Caregiver burden and stroke survivor domain satisfaction

The mean CBS total score (caregiver burden) was not significantly correlated with any of the 11 stroke survivor domain satisfaction mean scores.

#### Caregiver burden and stroke survivor quality of life

The mean CBS total score (caregiver burden) was not significantly correlated with any of the three stroke survivor overall quality of life mean scores.

Table 27.

B.C. Caregiver Burden Correlated with B.C. Stroke Survivor Function and B.C. Stroke Survivor Health

B.C. Caregiver burden (CBS) correlated	B.C. Caregiver burden (CBS) correlated with B.C. stroke survivor variables using stroke		
using stroke survivor-caregiver data-set $(N = 111)$ :	survivor-caregiver data-set ( $N = 111$ ):		
Stroke survivor function (FEFA)	Stroke survivor healt	th - SF36	
FEFA $.23*$ P = 0.02 N = 103	Physical function	NS	
	Role physical	NS	
	Body pain	$30^{**} P = 0.002 N = 100$	
	General health	21* P = 0.04 N = 96	
	Vitality	NS	
	Social function	NS	
	Role emotional	NS	
	Mental health	NS	
NC - not significant at 0.05	A		

NS = not significant at 0.05

\* = significant at <0.05</pre>

**\*\*** = significant at <0.001

**5.** Stroke survivor quality of life correlated with stroke survivor domain satisfaction Table 28 shows each measure of stroke survivor quality of life (satisfaction with life as a whole, satisfaction with overall quality of life, and happiness with life as a whole) correlated with 11 mean stroke survivor domain satisfaction scores. All 33 correlations were statistically significant at p<0.05 or better.

# Stroke survivor: satisfaction with life as a whole & domain satisfaction

Mean scores for stroke survivor satisfaction with life as a whole significantly and positively correlated with all stroke survivor domain satisfaction dimensions at p<0.001, with cell

sizes ranging from 86 to 115. All correlations were positive which is usual for these sorts of measures according to Michalos (personal communication, February, 2002). Low mean scores for stroke survivor satisfaction with life as a whole correlate with low mean scores for stroke survivor domain satisfaction scores; and high mean scores for satisfaction with life as a whole correlate with high mean scores for domain satisfaction scores. The correlations between, mean stroke survivor satisfaction with life as a whole score, and the 11 mean stroke survivor satisfaction scores, were: home (r = .37), neighborhood as a place to live (.40), family relations (.45), living partner (.42), friendships (.45), health (.51), religious or spiritual fulfillment (.59), financial security (.32), recreation activities ( .47), self-esteem (.47), and overall standard of living (.40).

The two strongest correlations with mean stroke survivor satisfaction with life as a whole scores were mean stroke survivor satisfaction with religion/spiritual fulfillment scores and mean stroke survivor satisfaction with health scores. So, 35% of the variance in stroke survivor satisfaction with life as a whole may be attributed to stroke survivor satisfaction with religion or spiritual fulfillment, while 26% may be attributed to stroke survivor health. In the general population, satisfaction with living partner and satisfaction with family relations usually have the highest positive correlations for stroke survivors was remarkably different from the general population, and probably the difference is attributed to their poor health status.

Stroke survivor: satisfaction with overall quality of life & domain satisfaction Mean stroke survivor satisfaction with overall quality of life scores significantly and positively correlated with all mean stroke survivor domain satisfaction scores at p<0.05 (or better). The correlations between, mean stroke survivor satisfaction with overall quality of life score, and the 11 mean stroke survivor satisfaction scores, were: home (r = .31), neighborhood as a place to live (.26), family relations (.31), living partner (.22), friendships (.54), health (.62), religious or spiritual fulfillment (.57), financial security (.31), recreation activities (.67), self-esteem (.50), and overall standard of living (.49).

The two strongest correlations with mean stroke survivor satisfaction with overall quality of life scores were mean stroke survivor satisfaction with recreation scores and mean stroke survivor satisfaction with health scores. So, 45% of the variance in stroke survivor satisfaction with overall quality of life as a whole may be attributed to stroke survivor satisfaction with recreation and 38% may be attributed to satisfaction with health. In the general population, satisfaction with living partner and satisfaction with family relations, usually have the highest positive correlations for satisfaction with overall quality of life. In this case, the pattern for highest correlations for stroke survivors was remarkably different from the general population, and the difference may be attributable to their poor health status.

Stroke survivor: happiness with life as a whole & domain satisfaction Mean stroke survivor happiness with life as a whole scores significantly and positively correlated with all 11 mean stroke survivor domain satisfaction scores at p<0.05 (or better). The correlations between, the mean stroke survivor happiness with life as a whole score, and the 11 mean stroke survivor satisfaction scores, were: home (r = .31), neighborhood as a place to live (.22), family relations (.49), living partner (.40), friendships (.37), health (.30), religious or spiritual fulfillment (.45), financial security (.34), recreation activities (.46), self-esteem (.51), and overall standard of living (.46).

The two strongest correlations with mean scores for stroke survivor happiness with life as a whole were mean scores for stroke survivor satisfaction with self-esteem and mean scores for stroke survivor satisfaction with family relations. So, 26% of variance in stroke survivor happiness with life as a whole may be attributed to self esteem satisfaction and 24% may be attributed to family relations satisfaction. In this case, the pattern for highest correlations for stroke survivors was more like the general population.

Table 28.

B.C. Stroke Survivor Quality of Life Correlated with B.C. Stroke Survivor Domain Satisfaction

	B.C. Stroke survivor quality of life correlations using stroke			
	survivor data-set:			
B.C. Stroke survivor	Stroke survivor	Stroke survivor	Stroke survivor	
domain satisfaction:	satisfaction with life	satisfaction with	happiness with life	
	as a whole	overall QOL	as a whole	
Your home	Correlation = .37**	Correlation = .31**	Correlation = .31**	
	P=.000	P=.001	P=.001	
	N=112	N=107	N=108	
Your neighborhood as	Correlation = .40**	Correlation = .26**	Correlation = .22*	
a place to live	P=.000	P=.006	P=.019	
	N=114	N=109	N=110	
Your family relations,	Correlation = .45**	Correlation =.31**	Correlation =.49**	
generally	P=.000	P=.001	P=.000	
· · · · · · · · · · · · · · · · · · ·	N=114	N=109	N=110	
Your living partner	Correlation = .42**	Correlation =.22*	Correlation = $.40^{**}$	
(eg spouse)	P=.000	P=.042	P=.000	
	N=93	N=89	N=89	
Your friendships	Correlation = .45**	Correlation =.54**	Correlation = .37**	
	P=.000	P=.000	P=.000	
	N=112	N=107	N=108	
Your health	Correlation = .51**	Correlation = .62**	Correlation = .30**	
	P=.000	P=.000	P=.002	
	N=112	N=108	N=108	
Your religion or	Correlation = .59**	Correlation = .57**	Correlation = .45**	
spiritual fulfillment	P=.000	P=.000	P=.000	
	N=86	N=83	N=109	
Your financial	Correlation = .32**	Correlation = .31**	Correlation = $.34**$	
security	P=.001	P=.001	P=.000	
	N=113	N=109	N=109	
Your recreation	Correlation = .47**	Correlation = .67**	Correlation = .46**	
activities	P=.000	P=.000	P=.000	
	N=105	N=101	N=101	
Your self esteem	Correlation = .47**	Correlation = .50**	Correlation = .51**	
	P=.000	P=.000	P=.000	
	N=112	N=107	N=108	
Your overall standard	Correlation = .40**	Correlation = .49**	Correlation = .46**	
of living	P=.000	P=.000	P=.000	
	N=115	N=110	N=111	

The predictor variable, satisfaction with job, was not included because n was small.

\*

= significant at <0.05 = significant at <0.001 \*\*

### 6. Caregiver quality of life correlated with caregiver domain satisfaction

Table 29 shows each measure of caregiver quality of life (satisfaction with life as a whole, satisfaction with overall quality of life, and happiness with life as a whole) correlated with the 11 means of caregiver domain satisfaction scores. All 33 correlations were statistically significant at p<0.05 or better.

Caregiver satisfaction with life as a whole with caregiver domain satisfaction Mean caregiver satisfaction with life as a whole scores significantly and positively correlated with all 11 caregiver mean domain satisfaction scores at p<0.001. The correlations between, mean caregiver satisfaction with life as a whole score, and the 11 mean caregiver satisfaction scores, were: home (r = .47), neighborhood as a place to live (.38), family relations (.42), living partner (.58), friendships (.57), health (.56), religious or spiritual fulfillment (.46), financial security (.46), recreation activities (.56), self-esteem (.51), and overall standard of living (.57).

The two strongest correlations with mean caregiver satisfaction with life as a whole scores were caregiver satisfaction with living partner and caregiver satisfaction with friendships. So, 34% of the variance in caregiver satisfaction with life as a whole may be attributed to satisfaction with living partner and 32% may be attributed to satisfaction with friendships. Caregivers respond in a pattern like the general population on satisfaction with life as a whole. This result is remarkable, considering most of these caregivers (87%) are burdened from caring for their spouse. This finding may indicate that being a caregiver increases satisfaction with life as a whole.

**Caregiver:** satisfaction with overall quality of life & domain satisfaction Mean scores for caregiver satisfaction with overall quality of life significantly and positively correlated with all 11 mean scores for caregiver domain satisfaction at p<0.001. The correlations between, mean caregiver satisfaction with overall quality of life score, and the 11 mean caregiver satisfaction scores, were: home (r = .48), neighborhood as a place to live (.39), family relations (.46), living partner (.46), friendships (.61), health (.62), religious or spiritual fulfillment (.55), financial security (.50), recreation activities (.58), self-esteem (.50), and overall standard of living (.59).

The two strongest correlations with caregiver satisfaction with overall quality of life were caregiver satisfaction with health and caregiver satisfaction with friendships. In the ordinary population the highest and positive correlations with satisfaction with overall quality of life usually are satisfaction with living partner or satisfaction with family relations. So, 38% of the variance in caregiver satisfaction with overall quality of life may be attributed to satisfaction with health and 37% may be attributed to satisfaction with friendships. Caregiver satisfaction with overall quality of life is different than the general population. This difference could caused by the burden of caregiving or could reduce the burden of caregiving.

### Caregiver: happiness with life as a whole & domain satisfaction

Mean scores for caregiver happiness with life as a whole significantly and positively correlated with all 11 mean scores for caregiver domain satisfaction at p<0.001. The correlations between, mean caregiver happiness with life as a whole score, and the 11 mean caregiver satisfaction scores, were: home (r = .50), neighborhood as a place to live (.40), family relations (.50), living partner (.61), friendships (.53), health (.54), religious or spiritual fulfillment (.37), financial security (.39), recreation activities (.54), self-esteem (.48), and overall standard of living (.47).

The two strongest correlations with mean scores for caregiver happiness with life as a whole were mean scores for caregiver satisfaction with living partner and recreation. So, 37% of the variance in mean scores for caregiver happiness with life as a whole may be attributed to mean scores for caregiver satisfaction with living partner and 29% may be attributed to satisfaction with recreation. These results are more similar to those expected for the general population.

Table 29.

B.C. Caregiver Quality of Life Correlated with B.C. Caregiver Domain Satisfaction

B.C. Caregiver quality of life correlations using caregiver data-set:					
B.C. Caregiver	Caregiver	Caregiver	Caregiver happiness		
Domain satisfaction:	satisfaction with life	satisfaction with	with life as a whole		
	as a whole	overall QOL			
Your home	Correlation = .47**	Correlation = .48**	Correlation = $.50**$		
	P=.000	P=.000	P=.000		
	N=106	N=105	N=105		
Your neighborhood as	Correlation = .38**	Correlation = .39**	Correlation = $.40^{**}$		
a place to live	P=.000	P=.000	P=.000		
	N=107	N=106	N=106		
Your family relations,	Correlation = .42**	Correlation = .46**	Correlation = .50**		
generally	P=.000	P=.000	P=.000		
	N=108	N=107	N=107		
Your living partner	Correlation = .58**	Correlation = .46**	Correlation = .61**		
(eg spouse)	P=.000	P=.000	P=.000		
	N=100	N=99	N=99		
Your friendships	Correlation = .57**	Correlation = .61**	Correlation = .53**		
	P=.000	P=.000	P=.000		
	N=105	N=104	N=104		
Your health	Correlation = .56**	Correlation = .62**	Correlation = .54**		
	P=.000	P=.000	P=.000		
	N=108	N=107	N=107		
Your religion or	Correlation = .46**	Correlation = .55**	Correlation = .37**		
spiritual fulfillment	P=.000	P=.000	P=.000		
	N=87	N=85	N=86		
Your financial	Correlation = .46**	Correlation = .50**	Correlation = .39**		
security	P=.000	P=.000	P=.000		
	N=106	N=106	N=105		
Your recreation	Correlation = .56**	Correlation = .58**	Correlation = .54**		
activities	P=.000	P=.000	P=.000		
	N=104	N=104	N=103		
Your self esteem	Correlation = .51**	Correlation = .50**	Correlation = .48**		
	P=.000	P=.000	P=.000		
	N=107	N=106	N=106		
Your overall standard	Correlation = .57**	Correlation = .59**	Correlation = .47**		
of living	P=.000	P=.000	P=.000		
	N=107	N=106	N=106		

The predictor variable, satisfaction with job, was not included because n was small.

\*

= significant at <0.05 = significant at <0.001 \*\*

### Multivariate Analysis – quality of life

The third objective of the study was to determine the variables that best explained quality of life in combination with the other variables. Twelve sets of regressions were conducted. Three stroke survivor dependent variables for quality of life (satisfaction with life as a whole, satisfaction with overall quality of life, and happiness with life as a whole) were individually regressed on stroke survivor predictor variables (FEFA scores, SF-36 scores, and 11 domain satisfaction scores). The three stroke survivor dependent variables for quality of life were then individually regressed on caregiver predictor variables (CBS scores, SF-36 scores, and 11 domain satisfaction with life as a whole, satisfaction with overall quality of life (satisfaction with life as a whole, satisfaction with overall quality of life, and happiness with life as a whole, satisfaction with overall quality of life, and happiness with life as a whole, satisfaction with overall quality of life, and happiness with life as a whole, satisfaction with overall quality of life, and happiness with life as a whole) were individually regressed on caregiver predictor variables for quality of life (Satisfaction with life as a whole, satisfaction with overall quality of life, and happiness with life as a whole) were individually regressed on caregiver predictor variables (CBS scores, SF-36 scores, and 11 domain satisfaction scores). Lastly, the three caregiver dependent variables for quality of life were individually regressed with stroke survivor predictor variables (FEFA scores, SF-36 scores, and 11 domain satisfaction scores).

Stepwise regression analysis was tried using listwise, pairwise, and mean substitution to manage missing data on some variables. The cell sizes were so small with listwise and pairwise deletion, and so manufactured with mean substitution that attempts to apply multivariate analysis were abandoned.

#### **CHAPTER V**

# **DISCUSSION & CONCLUSION**

The origins of this research were deeply rooted in and cumulative over almost two decades of working in rehabilitation. It sought to better understand the impact stroke has on the lives of stroke survivors who live in the community and their caregivers, concepts such as recovery versus adjustment, and contradictions such as stroke survivors who have a very poor functional recovery but seemingly enjoy a high quality of life. To learn more about these things, community-dwelling stroke survivors who attend a stroke club and their caregivers were studied and described. Stroke survivors and caregivers were included in the study because having a stroke affects more people than just the person who had the stroke. Next, B.C. stroke survivors and B.C. caregivers were compared to other comparative groups; and relationships among their variables were examined using correlations. Finally, attempts to determine predictors for stroke survivor quality of life and caregiver quality of life through regression analyses had to be abandoned, as there were insufficient numbers of subjects.

# **Stroke Survivors**

The stroke survivors in this study were comparable to those described in the literature. The average age of the B.C. stroke survivors was 70 years old (range from 30-93), 70% were male, 77% were married, 93% were retired, 63% had grade 8-12 education, and 68% had an annual income below \$30,000. Stroke survivors estimated they had made a 73% adjustment to living with stroke, where 100% would be full adjustment. The average length of time since stroke was 6 years. There was an equal distribution of strokes affecting the right or left side of the body. Most stroke survivors (98%) had rehabilitation from at least one of: hospital

(78%), rehabilitation unit (54%), outpatients (55%), and home care (15%). Stroke survivors attended a stroke club on average 45 times per year for approximately 4 ½ years.

### Caregivers

The caregivers in this study were similar to those described in the literature. The average age of the B.C. caregivers was 65 years old, 74% were female, 92% were married, 69% were retired, 57% had a grade 8-12 education, 63% had an annual income below \$30,000, and 87% were the spouse of the stroke survivor. Caregivers estimated they had made an 83% adjustment to their role as caregiver, where 100% would be full adjustment. Most caregivers rated their preparation for being a caregiver as not prepared (59%). Most caregivers (85%) prepared for being a caregiver by using at least one of: medical staff, stroke club, educational material or talking to others.

# Function

In this study, stroke survivor function was skewed toward the independent end of the (Frail Elderly Functional Assessment) FEFA scale. These results could not be compared to other stroke survivor group(s), as a published study using the FEFA was not found.

The mean FEFA total score correlated significantly and negatively with stroke survivor: SF-36 physical functioning, SF-36 general health, and SF-36 social function. Although correlations do not suggest causality, it is likely that SF-36 physical functioning could predict FEFA results, SF-36 general health could predict FEFA results, and FEFA results could predict SF-36 social functioning. The mean FEFA total score correlated significantly and

negatively with the mean satisfaction with health score, but not with other domain satisfaction items. The mean FEFA total score correlated significantly and negatively with the mean satisfaction with overall quality of life score, but not with the other two quality of life measures. The mean FEFA total score had fewer correlations with stroke survivor variables than was expected from a rehabilitation perspective. The results from this study, only moderately support the assumption in rehabilitation that improved function improves health, life satisfaction, and quality of life. Where statistically significant correlations were found, they were in the direction expected. For example, high stroke survivor function (low FEFA mean score) correlated with: better physical function (SF-36 PF), better general health (SF-36 GH), better social functioning (SF-36 SF), greater satisfaction with health (domain satisfaction), and greater satisfaction with overall quality of life (overall quality of life measure).

The mean FEFA total score correlated significantly and positively with only one caregiver variable, the mean CBS total score. For example, a high mean FEFA total score (dependence) correlated with a high mean CBS total score (more burden), and the reverse would also be true. It was expected that mean FEFA scores and mean CBS scores would be correlated, and in a positive direction, and this was found. It was expected that these two variables would share a large portion of their variance, but this was not found, as they only shared 5% of their variance. In the literature reviewed, some studies suggest that caregiver or family factors can affect stroke survivor rehabilitation negatively (Alexander, Bugge & Hagen, 1990). The results of this study do not support this; the mean FEFA total score was

not correlated with any of the other caregiver variables (health, domain satisfaction, and quality of life).

In this study, the FEFA was selected to measure stroke survivor function because it was designed to measure function items that were relevant to caregiver burden and because the subject could fill it out. It is interesting to note, that the SF-36 physical function and SF-36 role physical scales, also measure some aspect of physical function. However, the mean FEFA total score and SF-36 physical functioning mean scores only shared 28% of their variance, and the mean FEFA total score and the SF-36 role physical did not share any variance. Also, while the mean FEFA scores were skewed at the independence end of the FEFA scale, the SF-36-physical function and SF36-role physical mean scores were skewed at the impaired end of the physical function/role physical scales. From these results, it appears that the description of function captured by the FEFA was too narrow and was inadequate for generalizing function for stroke survivors.

# Burden

In this study, B.C. caregivers had higher Caregiver Burden Scale (CBS) mean scores than those reported in a Swedish study of stroke survivor caregivers, where higher CBS scores mean more burden.

The mean CBS total score (caregiver burden) was significantly and negatively correlated with mean scores for all caregiver variables (8 caregiver SF-36 mean scores, 11 caregiver domain satisfaction mean scores; and 3 measures of quality of life). Although correlations do

not suggest causality, it is likely that a low CBS score would result in better caregiver SF-36 satisfaction with health score, rather than the reverse. That a low CBS score would result in greater satisfaction on the 11 domain satisfaction scores, rather than the reverse. That a low CBS score would result in higher overall quality of life, rather than the reverse. These findings are relevant to rehabilitation and stroke support groups whereby, a reduction in caregiver burden improves their health, domain satisfaction, and quality of life; or could it be that an improvement in the caregiver's health, domain satisfaction, and quality of life reduces their perceived burden.

The mean CBS total score (caregiver burden) was significantly with only three stroke survivor variables. The mean CBS total score was significantly and positively correlated with the mean stroke survivor FEFA total score. The mean CBS total score was significantly and negatively correlated with the stroke survivor SF-36 bodily pain score. The mean CBS total score was significantly and negatively correlated with the stroke survivor SF-36 general health. Although correlations do not suggest causality, it is likely that FEFA results influence the CBS scores; stroke survivor SF-36 bodily pain results influence the CBS scores; and that stroke survivor SF-36 general health results influence the CBS scores. These findings are relevant to rehabilitation and to stroke support groups. Interpreting these results suggest that improving stroke survivor function (lowering FEFA scores) will likely reduce caregiver burden (low CBS scores). Reducing stroke survivor pain (increasing SF-36 bodily pain scores) will likely reduce caregiver burden (lower CBS scores). And improving stroke survivor satisfaction with general health (increasing SF-36 general health score) will likely reduce caregiver burden (lower CBS scores). Reducing stroke survivor pain and improving stroke survivor general health benefits B.C. stroke survivors and their caregivers. This could be accomplished through more collaboration between health care professionals and stroke club members.

From this study, it is not known whether both caregiver and stroke survivor variables would contribute simultaneously to caregiver burden. A regression analysis was not possible as the sample size was too small. In the study done by Scholte op Reimer, de Haan, Rijinders, Limburg, and van den Bos (1998), they found that 14% of the variance in caregiver burden was attributed to stroke survivor disability and 33% of the variance in caregiver burden was explained by caregiver variables. All that we can say is that mean CBS scores (caregiver burden) are related to mean scores for some stroke survivor variables (FEFA, SF-36 bodily pain, SF-36 general health), as well as mean scores for all caregiver variables (8 SF-36 scales, 11 domain satisfaction items, and 3 caregiver quality of life measures).

# **Stroke Survivor Health**

The self-reported health status for B.C. stroke survivors was lower than all comparison groups on at least 7 out of the 8 SF-36 subscales. Compared to the New Zealand stroke survivor group, the most comparative group, B.C. stroke survivor mean scores were lower on all 8 SF-36 scores, and on some scales, considerably lower. What could account for the difference between New Zealand stroke survivors and B.C. stroke survivors? Can it be attributed to different nationalities, rehabilitation programs, or general health status? If the findings in this study are accurate, rehabilitation and stroke support groups could develop

community health programs to improve the poor self-reported health status of stroke survivors in B.C.

On looking at the 8 SF-36 scores within this B.C. stroke survivor group, the lowest mean scores were for SF-36 physical functioning and SF-36 role physical and the highest mean scores were for SF-36 mental health and SF-36 social functioning. While post-stroke depression is reported in the stroke survivor literature, the findings from this study suggest that mental health and social functioning were the B.C. stroke survivors' best assets. These results should be restricted to stroke survivors who attend a SRABC stroke club. As well, it is not known whether stroke survivors with good mental health and intact social functioning predominantly attend a stroke club, or whether attending a stroke club improves mental health and social functioning of stroke survivors. If the findings in this study are accurate, it may be beneficial to learn more about New Zealand rehabilitation programs and adapt them for B.C. stroke survivors.

# **Caregiver Health**

The mean SF-36 scores for B.C. caregivers were most similar to those reported for Australian caregivers and interestingly, were lower than those reported for the general population (except for SF-36 bodily pain) and people with minor medical conditions. These findings are interesting because caregivers are in fact a segment of the general population so their results should be similar. As well, as a group, caregivers do not collectively have an identified health problem, yet their health status is worse than people with minor medical conditions. Are these findings important? They are, because all things being equal, these finding

indicate that the burden of caregiving is a greater health risk than uncomplicated chronic medical conditions. If these findings are accurate, there are many implications. For example, medical practitioners should address the health status of caregivers, which could be overlooked in providing care to the stroke survivor; and rehabilitation programs and stroke support groups could work together to develop community health initiates that encourage and educate caregivers on how to improve their health status.

# **Domain Satisfaction**

Mean scores for 11 dimensions of domain satisfaction were compared among three groups, B.C. stroke survivors, B.C. caregivers, and the general population. Stroke survivors had a higher mean score on satisfaction with living partner, than the general population. This may be directly related to feeling gratitude and appreciation for their partner helping them in everyday living. A traumatic event like a stroke can challenge the relationship between the stroke survivor and their spouse, but for those couples who remain together 6-years poststroke, their relationship may be stronger than in the general population. Stroke survivors had a higher mean score on satisfaction with religion/spiritual fulfillment, than the general population. This is not unexpected given they survived an acute traumatic event which may cause them to think about the meaning of life. Spirituality relates to the realization of the 'ultimate purpose and meaning of life' and has a positive influence on physical health and recovery from chronic illness or disability (Riley, Perna, Tate, Forchheimer, Anderson & Luera, 1998). Spirituality can also be defined as the 'ability to live in the wholeness of life' and requires connectedness to one's self, with others, and with the rest of creation (Egan and DeLaat (1994). Perhaps there is an aspect to attending a stroke club that enables stroke

survivors to connect to themselves and to others. Stroke survivors had a higher mean score on satisfaction with financial security, than the general population. This may reflect a practical situation of having their finances arranged to ensure they have adequate resources to support themselves. Stroke survivors had a lower mean score on satisfaction with health, than the general population. Likely this reflects their low self-rated health status. Stroke survivors had a lower mean score on satisfaction activities, than the general population. Likely this reflects negative stroke effect that limit participation.

Caregivers, compared to the general population, had higher mean scores for satisfaction with religion/spiritual fulfillment and satisfaction with financial security. These results are reasonable given caregivers exposure to their living partner's mortality. The explanations given for stroke survivors probably apply to caregivers.

Stroke survivors, compared to caregivers, had lower mean scores for satisfaction with friendships, satisfaction with health, and satisfaction with self-esteem. Stroke survivors would lose friends because of the stroke and find it difficult to establish new friendships, while caregivers may solidify some existing friendships and establish new friendships as a result of their partner's stroke. Stroke survivors had lower satisfaction with health scores than their caregiver likely because their health status is worse than their caregiver's health status. Stroke survivors had lower satisfaction with self-esteem than their caregiver likely because their self-esteem, but would not directly affect their caregiver's self-esteem.
### **Quality of Life**

Mean quality of life scores were compared among B.C. stroke survivors, B.C. caregivers, and the general population. Stroke survivors had lower mean scores than the general population on all three measures of quality of life: satisfaction with life as a whole, satisfaction with overall quality of life, and happiness with life as a whole. Caregivers had lower mean scores than the general population for happiness with life as a whole. Stroke survivors had lower mean scores than caregivers for satisfaction with life as a whole and satisfaction with overall quality of life.

All three stroke survivor quality of life scores were statistically correlated with all 11 stroke survivor domain satisfaction mean scores. In the general population, the highest correlations are between the three measures of quality of life and satisfaction with living partner or family relations. The stroke survivors responded like the general population on only one measure of quality of life, satisfaction with family relations. It is interesting that satisfaction with partner did not have a high correlation with any of the three measures of quality of life. The stroke survivors were different from the general population on two measures of quality of life. This may be due to their poor health status, or it could be an adjustment to living with stroke, rather than a recovery to their pre-stroke status. The highest satisfaction items to overall quality of life were, satisfaction with: family relations, religion/spiritual fulfillment, health, recreation, and self-esteem. These findings may be particular to stroke survivors who attend a stroke club. The benefits of attending a stroke club require further research.

All three caregiver quality of life scores were statistically correlated with all 11 caregiver domain satisfaction mean scores. Caregivers respond in a pattern like the general population on two measures of quality of life: satisfaction with life as a whole and living partner; and happiness with life as a whole and living partner. Caregivers did not respond like the general population on the other measure of quality of life; this deviation from the general population may be due to the burden of caregiving or lower self-reported health scores. These findings show that caregivers are different than the ordinary population. This difference may be a negative outcome of the burden of caregiving or a coping mechanism in response to caregiver burden. Satisfaction items that had high correlations with the three measures of quality of life included satisfaction with: living partner, friendships, health, and recreation. It is interesting that satisfaction with family relations did not have a high correlation with any of the three measures of quality of life. It is possible that caregivers do not wish to burden family members.

According to Jongbloed (1994), stroke can affect or disrupt roles, relationships, structures in everyday living, and the forms of knowledge that underpin them. Such understanding reveals that the interpretation of the stroke event and social support may be just as important as physical function in determining the client's quality of life. According to Webster's dictionary, to recover is to regain a normal position or condition (as in health), while to adjust is to bring to a more satisfactory state, settle, resolve or adapt (as in well being). These findings suggest that 6-years post-stroke both stroke survivors and caregivers have adjusted (or continue to adjust) to living with a stroke, they have not recovered to how, and who, they were before the stroke.

**QUALITY OF LIFE** 

### Strengths of the study

Two hundred and thirty-two community-dwelling stroke survivors and caregivers living throughout British Columbia participated in this study. Eighteen SRABC stroke clubs and coordinators successfully distributed and collected questionnaires. The researcher was mostly satisfied with the design of the questionnaires. Using standardized tests especially those of such high caliber as the SF-36 permitted phenomenal comparisons on a wide range of dimensions. A lot of information about stroke survivors and caregivers was collected. The size of the study allowed some analysis to be done with confidence. The use of dyads allowed for some matching of stroke survivors to their caregivers when stroke survivorcaregiver analyses were done.

### Limitations of the Study

Many limitations could affect the validity and reliability of this research such that interpretations and conclusions should be guarded and tentative. Some of the limitations may include the following. Results cannot be generalized to groups outside the study, as clubs were short-listed and subjects volunteered. Some data and results may not be accurate or valid as they were collected from people with varying levels of impairment, disability and/or handicap. In fact, the data and results could be quite biased toward people who had physical and cognitive abilities to complete the 7- or 8-page questionnaire. Questionnaires may have been too long. The voices of stroke survivors least able to complete the questionnaires were likely not heard. The questionnaires were composed of previously published tests that had not been used in this combination before; the validity of this is unknown. Stroke function may not have been adequately measured with the FEFA as the distribution of scores was

skewed. Although the FEFA was designed for community-dwelling frail elderly it did not seem to differentiate stroke survivor's function. There were no published FEFA results found, so comparisons were not possible. For the CBS, there was only one published study found, so comparisons were limited. As well, the small number of subjects precluded regression analyses, so it was not possible to determine predictors for quality of life.

### **Recommendations for Further Research**

This study could be done again with some changes to correct the limitations outlined above. In a subsequent quantitative study, a larger sample size should be used in order to determine the predictors for stroke survivor quality of life and caregiver quality of life. As well, it would be interesting to do a qualitative study to look at the areas studied in this project. Some topics that could be explored include the concepts of recovery and adjustment, assumptions underlying level of function and health and quality of life in people who have a chronic disabling condition, the role of spirituality in recovery, the meaning of functional status to stroke survivors, and the role of family to list a few. The stroke survivors and caregivers who belong to the SRABC are an incredible resource to the research community; they can teach us much about recovery, adjustment and rehabilitation. Recognizing the limited resources of the SRABC, partnerships with research organizations capable of doing statistical analyses are called for. Within rehabilitation, it is of paramount importance to develop a single gold-standard tool to measure functional status of rehabilitation patients, especially for those who return to the community. This tool needs to be based in a rehabilitation framework, have statistical integrity, and be designed for self-administration or by proxy.

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# Appendix A: Rehabilitation Framework – based on WHO Conceptual Framework and Nagi's Functional Limitation Model

Organ Level	Person Level	Societal Level
Conditions:		
Pathology	Behavioral	Role assignment
Anatomy	Performance deficits	Environment and
Physiology	Difficulty carrying out	Social deficits
Mental	everyday activities or	
Physical	ADL's	
Psychological		

Key terms: "Impairment" Organ dysfunction	<b>←</b> →	<b>"Disability"</b> Difficulty with task	$\leftrightarrow$	"Handicap" Social disadvantage	
Limitations	in using ski	ills, performing activities, a	and fulfilling	g social roles	

Analysis: Use diagnostic descriptors	Use performance or behavioral descriptors	Use role descriptors	
Func	tional assessment of abilities and activit	ies	
Func	ctional assessment of abilities and activit	ies	

Intervention:		
Medical &	Adaptative equipment;	Supportive services &
Restorative therapy	Reduction of physical & attitudinal barriers	Social policy changes
All needing long-r	ange coordination to improve and ma	intain function

Source: U.S. Department of Health and Human Services, 1995

### Appendix B: Letter of Request to the Director of the SRABC

### To:

Mr Barry Fondrick, Director Stroke Recovery Association of British Columbia 109-119 West Pender, Vancouver, BC, V6B 1S5

### From:

Anne-Marie Draper, Master's Candidate in Community Health, UNBC 2923 Ridgeview Drive, Prince George, BC, V2K 3T5

### March 7, 2001

#### Dear Mr Fondrick

Thank you for our meeting in January this year. It was exciting to speak with you and learn more about your organization.

Thank you also for your time, information and support for the research project I am working on. The project focuses on the quality of life of people who have a stroke and their personal unpaid caregiver.

Presently I have almost completed the questionnaires. I hope to send out approximately 200 questionnaire packages to clubs throughout the province and in particular Prince George and Vanderhoof clubs. I will contact the club coordinators to explain the study and mail questionnaires. I will provide a pre-paid envelope for the coordinators to return completed surveys to me.

At the moment I would ask you if it was possible to get a list of clubs that would represent the whole province (north to south, east to west), large cities and smaller cities and large and small clubs.

I hope to hear from you soon. I thank you for your support.

Sincerely,

Anne-Marie Draper

Phone (work) (250) 565-2592 or home (250) 962-2923 Fax (work) (250) 565-2584 or home (250) 962-2923 Email (work) <u>adraper@pgrhosp.hnet.bc.ca</u> or home <u>draper@pgonline.com</u>

### Appendix C: Letter to SRABC Stroke Club Coordinators

April 28, 2001

### Dear

It was nice to speak to you on the phone about my research project. It was a wonderful experience for me to meet so may people dedicated to running stroke clubs around the province.

Thank you for being willing to support my research project. I have tried to make it as easy as possible for you. As a stroke club coordinator I would be asking you to:

- 1. receive the mailed packages
- 2. read the green information sheet as it has information about myself, who my professor is a the UNBC in Prince George and a summary of the research project (every envelope has a green information sheet)
- 3. explain to stroke club members about the study and ask for volunteers
- 4. a Stroke person is anyone who has had a stroke. A Caregiver is someone who helps the stroke person in everyday living but is not paid to do so. The caregiver may help a little or a lot. If he/she call themselves or thinks of themselves as a caregiver then they are.
- 5. provide the questionnaire envelopes
- 6. collect the questionnaire envelopes
- mail them back to me in the pre-paid self-addressed envelope by August 1, 2001

I would hope that you could encourage members to complete the surveys and return them to you. The more voices are heard, the better. The more questionnaires returned, the more the results would represent all people. We will all benefit from the results of this research. I have included a list of all the clubs participating. If you have extra surveys – you could if another club needs more. I only printed and distributed 220.

I will not be available by telephone from May 5-July 2 as am out of the country. During this time I will be checking my email regularly so if you have questions please use email (if you have it). My email address is (<u>draper@pgonline.com</u>). I will try to contact you in July to see how things are going. You can also try phoning Alex Michalos my professor at UNBC (250 960-6697).

The results of the research will be shared. I will give Barry Fondick a copy of my thesis, I will write some articles for the Voice of the Turtle and if/when possible I will try to do a presentation.

Thank you very much.

### Sincerely, Anne-Marie Draper

Appendix D: Questions & Answers About the Research

## Questions & Answers About the Research

To: Stroke Survivors & Personal Caregivers who may fill out the questionnaires & Stroke Club Coordinators who may help recruit subjects From: Anne-Marie Draper, Student UNBC Date: April 2001

This is a description of the research project that I am doing for my master's degree. Please read this information prior to taking part in my project. <u>Thank you</u>, Anne-Marie.

### Title of the research project is: Quality of life of community living stroke survivors and caregivers in BC

Who is doing the research? Anne-Marie Draper. I am a <u>student</u> at the University of Northern British Columbia (UNBC) in Prince George, BC. I <u>work</u> as the Chief OT at Prince George Regional Hospital, in Prince George.

Who is the supervising the research? Dr. Alex Michalos, UNBC professor, Director of the Institute for Social Research and Evaluation

What type of project is this? It is a research project for my Masters of Community Health.

What is the purpose of the research? The purpose is to learn more about the quality of life of stroke survivors and their caregivers with the hope this may improve quality of life.

What are the potential benefits from the study? I hope the research will benefit the people who are stroke survivors and their personal caregivers.

What are the potential risks of the study? Some people may be sensitive to some of the questions. This is not the intention. Please contact my advisor or myself if you have concerns.

How will subjects be chosen for this research? Subjects will be recruited from stroke clubs run by the Stroke Recovery Association of B.C. I have approval from Barry Fondrick, the Provincial Coordinator of the Stroke Recovery Association of BC. He has assisted me in choosing some clubs throughout BC. The coordinators of the stroke clubs will tell club members about the research to help to get subjects. Subjects will volunteer for the study.

### Who are the subjects in the study? There are 2 groups in this study.

A person in the <u>Stroke Survivor Group</u> will be someone who has had a stroke and lives in the community. Stroke survivors who live in a care facility are not included in this study.

A person in the <u>Caregiver Group</u> will be someone who helps the person who had a stroke in their everyday living, but is not paid to do. A caregiver may be a wife or husband, son or daughter, neighbour or friend. Caregivers will volunteer for the study. Paid caregivers such as homemakers are not included in this study.

**Do subjects volunteer for the study?** Yes, participation in this research project is 100% voluntary. You may choose to take part, not take part or withdraw from this study at any time. You do not need to have a reason. It will not affect you in any way.

### What are you asked to do if you volunteer for this study?

<u>Stroke Subjects & Caregiver Subjects</u> You are asked to complete a questionnaire. This may take you about 30-45 minutes. To answer questions you will – circle a letter or a number, check a box or fill in a blank with a short answer. You may take breaks any time while filling out the questionnaire. You may ask someone else to help you – as long as the answers are your own views. When finished please return questionnaires to your Stroke Club Coordinator.

<u>Stroke Club Coordinator</u> You are asked to inform members of your club of the research project, hand out the questionnaire package, collect the completed questionnaires and return the questionnaires to me. I would like to have the questionnaires returned to me by <u>August 1, 2001</u>. I hope to complete my project in the fall for graduation.

Will you be anonymous? Yes, you are completely anonymous because you do not give me your name. Any information presented or written about this study will <u>not</u> describe you as an individual; only summaries of the groups will be used.

Who will have access to what you say? Only myself and Dr Alex Michalos.

Is the information confidential? Yes, information will be confidential.

How will information be stored? Information will stored in a room with a lock and key.

How long will the information be stored for? It will be stored indefinitely.

Who	do you	contact	if you	have	questions	about	the study	or th	e question	inaire?

2923 Ridgeview Drive, Prince George, BC, V2K 3T5
Home = (250) 962-2923 or Phone work = (250) 565-2581
draper@pgonline.com

Alex Michalos Phone work = (250) 960-6697

### Who do you contact if you have a complaint about the study?

The Office of Research and Graduate Studies, UNBC, (250) 960-5820

How do you get a copy of research results? My thesis will be a public document and will be available at the UNBC library or by asking me for a copy. I will provide the Stroke Recovery Association of BC with a copy of my research findings, write some short articles for the Voice of the Turtle newsletter and do presentations as requested. *I thank you very much, Anne-Marie Draper* 

<b>Appendix E:</b>	<b>Stroke Survivor</b>	<b>Quality of Life</b>	Questionnaire
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For office use only	#
	April, May, June, July 2001

## Stroke Survivor Quality Of Life Questionnaire

Having a stroke can affect people in many different ways.

The purpose of this research is to learn more about the quality of life, health and everyday living of people who have had a stroke and their personal caregiver.

There are 4 parts to this questionnaire:

Part 1 - asks questions about how you do everyday activities

Part 2 - asks questions about your health

Part 3 - asks questions about your quality of life and life satisfaction

Part 4 - asks some demographic questions

### Instructions

- 1. First Please give the Caregiver Questionnaire to your main unpaid caregiver.
- 2. Next Please complete this Stroke Survivor Questionnaire as best you can.
  - For most questions you will circle an answer, tick a box or fill in a blank.
  - You can take breaks and come back to the questions.
  - You can ask someone to help as long the answers are your own views.
- 3. When finished Please return both questionnaires to your Stroke Club Coordinator.

Thank you, Anne-Marie Draper

 Stroke

 How long ago did you have your stroke? (Please fill in one blank)

 \_\_\_\_\_\_Months Ago.
 Or
 \_\_\_\_\_Years Ago.

 If you have not had a stroke - stop - please return this questionnaire now.

### Caregiver

A personal caregiver is someone who helps in everyday living, but is not paid to do so.

Do you have a personal caregiver? (Please circle one) Yes or No If 'Yes' – please give the Caregiver Questionnaire to your main personal caregiver.

If 'No' - if you do not have a personal caregiver - stop - please return this questionnaire now.

### Part I – Questions about Everyday Activities

### 1.sa Are you able to walk? (Please circle <u>one</u> answer)

- a. Yes, without help
- b. Yes, with a cane or walker
- c. Yes, with the help of another person
- d. Not at all

#### 2. sa Can you transfer out of bed? (Please circle one)

- a. Yes, alone without a transfer board or other assistance device
- b. Yes, with the help of a transfer board or other device
- c. Yes, with the help of one or more person
- d. Yes, with the help of both another person and some assistive devices
- e. Not at all

### 3. sa Are you able to turn over on your side in bed? (Circle one)

- a. Yes, without help
- b. Yes, with assistive device(s)
- c. Yes, with some help from another person
- d. No, must be turned

### 4. sa Are you able to wash dishes? (Circle one)

- a. Yes
- b. No

### 5. sa Are you able to prepare your own hot dinner? (Circle one)

- a. Yes
- b. No, but am able to heat up already prepared meals
- c. No, but am able to make a peanut butter and jelly sandwich
- d. Not at all

## 6. sa Are you able to manage money (paying bills, keep check book, etc)? (Circle one)

a. Yes

- b. Partially, but not major bills and balancing a check book
- c. Sign checks but unable to handle even minor transactions
- d. No

### 7. sa Are you able to use the telephone? (Circle one)

- a. Yes, including dialing and answering the phone
- b. Yes, but unable to dial
- c. Yes, but am not able to dial or pick up receiver
- d. No

### 8. sa Are you able to eat by mouth, including feeding yourself? (Please circle one answer)

- a. Yes, without help
- b. Yes, with assistive device(s)
- c. No, but can eat if fed
- d. No, but can give own tube feeding
- e. No, must be tube fed

## 9. sa Are you able to dress yourself in pants or skirt, shirt or blouse, slip on shoes and socks - if clothes are placed out? (Circle one)

- a. Yes, without help of either a person or assistive device
- b. Yes, with assistive device(s)
- c. Partially, but some help is required from another person
- d. No, completely dependent on another person

## 10. sa Are you able to dress yourself in a robe and slippers if both are placed out? (Circle one)

- a. Yes, without help of either a person or assistive device
- b. Yes, with assistive device(s)
- c. Partially, but some help is required from another person
- d. No, completely dependent on another person

### 11. sa Are you able to bathe in a tub or shower yourself? (Circle one)

- a. Yes, without help
- b. Yes, with assistive device(s), eg. tub chair or grab bar
- c. Partially, but some help is required from another person
- d. Partially, but some help is required from another person and assitive device(s)
- e. No, completely dependent on another person

12. sa If the answer to #11 was 'e' (completely dependent on another person) Are you able to sponge bath yourself? (Circle <u>one</u>)

- a. Yes, without help
- b. Partially, but some help is required from another person
- c. No, completely dependent on another person
- d. Not applicable (#11 was a, b, c or d)

### 13. sa Are you able to use the toilet, including getting to the bathroom? (Circle one)

- a. Yes, without help
- b. Yes, with assistive device(s)
- c. Yes, with some help from another person
- d. Yes, with help from another person and assistive device(s)
- e. No, unable to use toilet in bathroom

If you answered #13 as 'a' (yes without help)  $\rightarrow$  skip to #16

14. sa If you answered #13 above as 'e' (unable to use toilet in the bathroom), Are you able to use a bedside commode? (*Please circle one answer*)

- a. Yes, without help
- b. Yes, with assistive device(s)
- c. Yes, with some help from another person
- d. Yes, with help from another person and assistive device(s)
- e. No, unable to use bedside commode
- f. Not applicable (#13 was a, b, c, or d)

If you answered #14 as 'a' (yes, without help) skip to #16.

15. sa If you answered #14 above as 'e' (unable to use bedside commode), Are you able to use a bedpan/urinal? (Circle one)

- a. Yes, without help
- b. Yes, with help
- c. No, am unable to recognize bladder fullness or bowel movement
- d. No, I have an ostomy and someone else empties the bag
- e. Not applicable (#13 or #14 was a, b, c or d)

### 16. sa Are you able to sit up? (Circle one)

- a. Yes without help
- b. Yes, with assistive device(s)
- c. Yes, but some help is required from another person
- d. No

### 17. sa Are you able to grasp a cup or a cloth in your hands? (Circle one)

- a. Yes, either hand
- b. Yes, but only with one hand
- c. No

### 18. sa Are you able to reach out past your nose? (Circle one)

- a. Yes, with arm fully extended at shoulder level
- b. Yes, but can not fully extend at shoulder level
- c. No

### 19. sa Are you usually able to take your own medication every day? (Circle one)

- a. Yes, without help
- b. Yes, if medication doses are set out by another person
- c. No, must have medication administered by another person
- d. No, do not take medication on a daily basis

## Part 2 – Questions about your Health

<b>1</b> .sh	In general, woul	d you say your health is:	(Please circle o	ne)	
	1	2	3	4	5
	Excellent	Very Good	Good	Fair	Poor

## 2.sh Compared to one year ago, how would you rate your <u>health</u> in general now? (Circle <u>one</u>)

- 1. much better now than one year ago
- 2. somewhat better now that one year ago
- 3. about the same as one year ago
- 4. somewhat worse than one year ago
- 5. much worse than one year ago
- 3.sh The following items are activities you might do in a typical day. Does your health now limit you in these activities? If so, how much? (For each one please  $\sqrt{the appropriate column}$ )

č		Yes	Yes	No
		Limited	Limited	Not limited
		A lot	A little	At all
a)	Vigorous/heavy activities ie			
	strenuous sports/house/yard work	()	()	()
b)	Moderate - ie laundry, clean, vacuum, bowl	()	()	()
c)	Lifting or carrying groceries	()	()	()
<b>d</b> )	Climbing several flights of stairs	()	()	()
<b>e</b> )	Climbing one flight of stairs	()	()	()
<b>f</b> )	Bending, kneeling, or stooping	()	()	()
<b>g</b> )	Walking more than 1.6 kms (1 mile)	()	()	()
h)	Walking several blocks	()	()	()
i)	Walking one block	()	()	()
j)	Bathing or dressing yourself	()	()	()

4.sh During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as result of your physical health? (For each – check  $\sqrt{\text{'yes' or 'no'}}$ )

		Yes	No
a)	Cut down on the amount of time you spent on work or other activities	()	()
b)	Accomplished less than you would like	()	()
<b>c</b> )	Were limited in the kind of work or other activities	()	()
<b>d</b> )	Had difficulty performing work/other activities eg it took extra effort	()	()

Yes

()

()

No

()

()

5.sh	During the past 4 weeks, have you had any of the following problems with your work or other
	regular daily activities as result of any emotional problems (such as feeling depressed or
	anxious)? (For each - check $\sqrt{\text{'yes' or 'no'}}$

a)	Cut down on the amount of time you spend on work/other activities	()	()
----	---	----	----

- b) Accomplished less than you would like
- c) Didn't do your work/other activities as <u>carefully</u> as usual

6.sh

During the	past 4 weeks, to what ext	ent have your physical h	ealth or emotiona	al problems
interfered	with your normal social ac	tivities with family, friend	ds, neighbors or gi	oups?
(Circle one	e)			
1	2	3	4	5
Not at all	Slightly	Moderately	Quite a bit	Extremely

7.sh	How much	bodily pain hav	ve you had	during the past 4 w	eeks? (Plea	se circle <u>one</u> )	
	1	2	3	4	5	6	
	None	Very mild	Mild	Moderate	Severe	Very severe	

8.sh During the past 4 weeks, how much did pain interfere with your normal work (including work both outside the home and housework)? (Please circle one)
 1
 2
 3
 4
 5

1	2	5	-	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

# 9.sh How much of the time during the past 4 weeks have you been feeling the following? For each - please check $\sqrt{}$ the one answer that comes closest to the way you have been feeling ...

	All of the	Most of the	A good bit of	Some of the	A little of the	None of the
	time	time	the time	time	time	time
Did you feel full of pep?	()	()	()	()	()	()
Have you been a very nervous person?	()	()	()	()	()	()
Have you felt so down in the dumps						
that nothing could cheer you up?	()	()	()	()	()	()
Have you felt calm & peaceful?	()	()	()	()	()	()
Did you have a lot of energy?	()	()	()	()	()	()
Have you felt downhearted & blue?	()	()	()	()	()	()
Did you feel worn out?	()	()	()	()	()	()
Have you been a happy person?	()	()	()	()	()	()
Did you feel tired?	()	()	()	()	()	()
	Did you feel full of pep? Have you been a very nervous person? Have you felt so down in the dumps that nothing could cheer you up? Have you felt calm & peaceful? Did you have a lot of energy? Have you felt downhearted & blue? Did you feel worn out? Have you been a happy person? Did you feel tired?	All of the time Did you feel full of pep? () Have you been a very nervous person? () Have you felt so down in the dumps that nothing could cheer you up? () Have you felt calm & peaceful? () Did you have a lot of energy? () Have you felt downhearted & blue? () Did you feel worn out? () Have you been a happy person? () Did you feel tired? ()	AllMost of the of the timeDid you feel full of pep?( )Have you been a very nervous person?( )Have you felt so down in the dumps that nothing could cheer you up?( )Have you felt calm & peaceful?( )Did you have a lot of energy?( )Have you felt downhearted & blue?( )Did you feel worn out?( )Have you been a happy person?( )Did you feel tired?( )	AllMostA good bit ofOf theof theof thebit oftimetimetimethe timeDid you feel full of pep?( )( )( )Have you been a very nervous person?( )( )Have you felt so down in the dumpsthat nothing could cheer you up?( )( )Have you felt calm & peaceful?( )( )( )Did you have a lot of energy?( )( )( )Have you felt downhearted & blue?( )( )( )Did you feel worn out?( )( )( )Did you feel tired?( )( )( )	AllMostA goodSome of the bit ofSome of the timeDid you feel full of pep?()()()()Have you been a very nervous person?()()()()Have you felt so down in the dumps that nothing could cheer you up?()()()()Have you felt calm & peaceful?()()()()Did you have a lot of energy?()()()()Have you felt downhearted & blue?()()()()Did you feel worn out?()()()()Did you feel ired?()()()()	All of the of the timeMost of the of the timeA good bit ofSome of the of the of the timeA little of the of the timeDid you feel full of pep?( )( )( )( )( )Have you been a very nervous person?( )( )( )( )( )Have you felt so down in the dumps that nothing could cheer you up?( )( )( )( )( )Have you felt calm & peaceful?( )( )( )( )( )( )Did you have a lot of energy?( )( )( )( )( )( )Have you felt downhearted & blue?( )( )( )( )( )( )Did you feel worn out?( )( )( )( )( )( )Did you feel tired?( )( )( )( )( )( )

10.sh During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? (Circle one)

1	2	3	4	5	
All of	Most of	Some of	A little of	None of	
the time	the time	the time	the time	the time	

11.sh	How true or false is each of the following statements for you? (Put a check $$ in the column							
			Definitely	Mostly	Don't	Mostly	Definitely	
			True	True	Know	False	False	
	a)	I seem to get sick a little easier						
		than other people	()	()	()	()	()	
	<b>b</b> )	I am as healthy as anyone I know	()	()	()	()	()	
	c)	I expect my health to get worse	()	()	()	()	()	
	<b>d</b> )	My health is excellent	()	()	()	()	()	

## Part 3 – Questions about Quality of Life and Life Satisfaction

Here are some services and other things that affect people today. Please indicate how satisfied you are with each of them.

For each question - please circle one number between 1 - 7 using the following guide:

1 Very <u>Dis</u> satisf	2 Somewhat fied Dissatisfied	3 A little Dissatisfied	4 Abo Bala Neu	out Even anced itral	5 A li Sati	ttle sfied	6 Somev Satisfie	vhat ed	7 Very <u>Sat</u> isfied	0 N/A
How sat	isfied are you with	V Dis	ery satisf	ïed	B	alance	d		Very <u>Sat</u> isfied	N/A
1.ss You	ir home		1	2	3	4	5	6	7	0
2.ss You	r neighborhood as a	a place to live	1	2	3	4	5	6	7	0
3.ss You	ur family relations,	generally	1	2	3	4	5	6	7	0
4.ss You	ur living partner (eg	spouse)	1	2	3	4	5	6	7	0
5ss Ho	w you feel about life	e as a whole	1	2	3	4	5	6	7	0
6.ss You	ur job		1	2	3	4	5	6	7	0
7.ss Yo	our friendships		1	2	3	4	5	6	7	0
8.ss Yo	our health		1	2	3	4	5	6	7	0

9.ss	Your religion or spiritual fulfillment	1	2	3	4	5	6	7	0
<b>10</b> ss	Your overall quality of life	1	2	3	4	5	6	7	0
11.ss	Your financial security	1	2	3	4	5	6	7	0
12.ss	Your recreation activities	1	2	3	4	5	6	7	0
13.ss	Your self esteem	1	2	3	4	5	6	7	0
14.ss	Your overall standard of living	1	2	3	4	5	6	7	0

15ss Consid	dering your	life as a whole, i	how <u>happy</u> w	ould you say	you are?	(Please cir	cle <u>one</u> )
1	2	3	4	5	6	7	0
Very	Somewhat	A Little	Evenly	A Little	Somewhat	Very	NA
Unhappy	Unhappy	Unhappy	Balanced	Нарру	Нарру	Happy	

## Part 4 Personal Information

1.sp	Your present age:	years	old (Fill	in your age	in years)
<b>2</b> .sp	Are you:	(a) Female	(b)	) Male	(Circle one)
3.sp.	What is the highest l	evel of schooling	complete	d? (Circle	one please)
	a. Grade 1 – 7		с.	College/Te	chnical
	b. Grade 8 – 12		d.	University	
4.sp.	What is your presen	t marital status?	(Circle o	one please)	
	a. Married		d.	Widowed	1
	b. Common-lay	w partner	e.	Divorced	ł
	c. Single		f.	Separate	d
5.sp.	What is your employ	ment/productivi	ty status?	(Please ci	rcle <u>all</u> that apply)
	a. Employed		d.	Homema	aker
	b. Own your own b	ousiness	e.	Student	
	c. Retired		f.	Voluntee	r
<b>6</b> .sp	What was your last	year's income lev	el? (Circ	le one pleas	e)
	a. Less than \$20,00	0 per year	d.	\$40,000 to	50,000 per year
	b. \$20,000 to \$30.0	00 per year	e.	\$50,000 to	60,000 per year
	c. \$30,000 to 40,00	0 per year	f.	over \$60,0	00 per year
-	XX/1 * 1 . * 1 6			(Circle or	

# 7.spWhich side of your body did the stroke affect? (Circle one please)<br/>a. Left arm/legb. Right arm/leg

- Did you have therapy for your stroke? (e.g. Physiotherapy, Occupational Therapy, 8.sp Speech Language Pathology and/or Recreation Therapy)
  - a. No I did not have any therapy for my stroke
  - b. Yes I did have therapy for my stroke (Check off and complete all that apply):
    - In a Hospital for months
    - months □ In a Rehabilitation/Therapy Unit for
    - □ As an Outpatient at a hospital and/or private clinic months months
    - □ In my home through Home Care for
- Right now, how adjusted are you to living with a stroke? (Please fill in the blank with a 9.sp number between 0% = not adjusted and 100% = fully adjusted) %

#### Right now, do you attend a Stroke Club? 10.sp

- a. No
- For months. Or b. Yes - for how long? For \_\_\_\_\_ years. - how often do you attend club or other functions? = times a year.

 $\rightarrow$  This ends the questionnaire - please return it to your Stroke Club Coordinator.

Thank you very much, Anne-Marie Draper

Appendix F: Caregiver Quality of Life Questionnaire

For office use only #\_\_\_\_\_\_ April, May, June, July 2001

## Caregiver Quality Of Life Questionnaire

Being a caregiver for someone who has had a stroke affects people in different ways.

The purpose of this research is to learn more about the quality of life, health and everyday living of people who have had a stroke and their personal caregiver.

There are 4 parts to this questionnaire:

Part 1 - asks questions about the burden of being a caregiver

Part 2 - asks questions about your health

Part 3 - asks questions about your quality of life and life satisfaction

Part 4 - asks some demographic questions

### Instructions

- 4. First Please give the Stroke Survivor Questionnaire to the person who had the stroke.
- 5. Next Please complete this Caregiver Questionnaire as best you can.
  - For most questions you will circle an answer, tick a box or fill in a blank.
  - You can take breaks and come back to the questions.
  - You can ask someone to help as long the answers are your own views.
- 6. When finished Please return both questionnaires to your Stroke Club Coordinator.

Thank you, Anne-Marie Draper

A personal caregiver is someone who helps in everyday living, but is not paid to do so. How long have you been a caregiver to the person who had the stroke? (Please complete) For \_\_\_\_\_ months. Or for \_\_\_\_ years. What is your relationship to the person who had the stroke? (Please tick one) I am his or her \_\_\_\_\_\_. Wife or Husband – legal, common-law, live-in partner Adult Child – son or daughter, step-son, step-daughter Parent – mother, father, step-mother, step-father Sibling – sister, brother, step-sister, step-brother Relative –aunt, uncle, niece, nephew Friend or Neighbour Other If you are <u>not</u> a personal caregiver – stop - please return this questionnaire now.

## Part I – Questions about Caregiver Burden Note - the phrase 'your relative' refers to the stroke person you help or give care to

1.cb Do you find yourself facing purely practical problems in the care of your relative that you think are difficult to solve? (Please circle <u>one</u> answer)

l - Not at all	2 - Seldom	3 - Sometimes	4 - Often

2.cb Do you think you have to shoulder too much responsibility for your relative's welfare? (Circle one)

 1 - Not at all
 2 - Seldom
 3 - Sometimes
 4 - Often

<b>3</b> .cb	Do you sometimes	feel as if you would	like to run away from	the entire situation you
	find yourself in? (C	Circle <u>one</u> )		
	1 - Not at all	2 - Seldom	3 - Sometimes	4 - Often

4.cb	Do you feel tired a	nd worn down? (Cir	cle <u>one</u> )	
	1 - Not at all	2 - Seldom	3 - Sometimes	4 - Often

- 5.cbDo you feel tied down by your relative's problem? (Circle one)1 Not at all2 Seldom3 Sometimes4 Often
- 6.cb Do you find it mentally trying to take care of your relative? (Circle <u>one</u>) 1 - Not at all 2 - Seldom 3 - Sometimes 4 - Often

7.cb Do you think your own health has suffered because you have been taking care of your relative? (*Circle one*)
 1 - Not at all
 2 - Seldom
 3 - Sometimes
 4 - Often

8.cb Do you think you spend so much time with your relative that the time for yourself is insufficient? (Circle one)
 1 - Not at all
 2 - Seldom
 3 - Sometimes
 4 - Often

9.cb Do you avoid inviting friends/acquaintances home because of your relative's problems? (Circle one)
 1 - Not at all
 2 - Seldom
 3 - Sometimes
 4 - Often

10.cb	Has your <b>social li</b> 1 - Not at all	fe, eg with family and 2 - Seldom	friends, <b>been lessened</b> ? 3 - Sometimes	(Please circle <u>one</u> .) 4 - Often
<b>11</b> .cb	Has your relative'	s problems <b>prevented</b> our life? (Circle one)	you from doing what yo	u had planned to do
	1 - Not at all	2 - Seldom	3 - Sometimes	4 - Often
12.cb	Have you a fe	eling that life has	treated you unfairly	? (Circle one)
	1 - Not at all	2 - Seldom	3 - Sometimes	4 - Often
13.cb	Had you expected	that life would be diff	erent than it is at your a	ge? (Circle <u>one</u> )
	1 - Not at all	2 - Seldom	3 - Sometimes	4 - Often
14.cb	Do you feel lonely	y and isolated because	of your relative's proble	ems? (Circle <u>one</u> )
	1 - Not at all	2 - Seldom	3 - Sometimes	4 - Often
15.cb	Do you find it <b>phy</b>	vsically trying to take	care of your relative? (C	Sircle <u>one</u> )
	1 - Not at all	2 - Seldom	3 - Sometimes	4 - Often
16.cb	Have you experier your relative? (Ci	nced <b>economic sacrifi</b> o <i>rcle <u>one</u>)</i>	ce because you have been	n taking care of
	1 - Not at all	2 - Seldom	3 - Sometimes	4 - Often
17.cb	Are you sometime	s <b>ashamed</b> of you rela	tive's behavior? (Circle	<u>one</u> )
	1 - Not at all	2 - Seldom	3 - Sometimes	4 - Often
18.cb	Do you ever feel o	ffended and angry w	ith your relative? (Circle	e <u>one</u> )
	1 - Not at all	2 - Seldom	3 - Sometimes	4 - Often
19.cb	Do you feel emba	rrassed by your relativ	ve's behavior? (Circle or	<u>ne</u> )
	l - Not at all	2 - Seldom	3 - Sometimes	4 - Often
20.cb	Does the physical	environment make it	troublesome for you tak	ing care of
	your relative? (Ci	rcle <u>one</u> )	2 Comptinger	1 08
	I - Not at all	2 - Seldom	3 - Sometimes	4 - Ollen

- **21.cb** Do you worry about not taking care of your relative in the proper way?(Circle one)1 Not at all2 Seldom3 Sometimes4 Often
- 22.cb Is there anything in the neighborhood of your relative's home making it troublesome for you to take care of your relative? (Circle one)

  Not at all
  Seldom
  Sometimes
  Often

### Part 2 – Questions about your Health

1.ch	In general, would	d you say your health i	s: (Please circle one	2)	
	1	2	3	4	5
	Excellent	Very Good	Good	Fair	Poor

2.ch Compared to one year ago, how would you rate your <u>health</u> in general now? (Circle <u>one</u>)

- 1. much better now than one year ago
- 2. somewhat better now that one year ago
- 3. about the same as one year ago
- 4. somewhat worse than one year ago
- 5. much worse than one year ago
- 3.ch The following items are activities you might do in a typical day. Does your health now limit you in these activities? If so, how much? (For each please  $\sqrt{the appropriate column}$ )

		Yes	Yes	No
		Limited	Limited	Not limited
		A lot	A little	At all
a)	Vigorous/heavy activities ie			
	strenuous sports/house/yard work	()	()	()
b)	Moderate - ie laundry, clean, vacuum, bowl	()	()	()
c)	Lifting or carrying groceries	()	()	()
d)	Climbing several flights of stairs	()	()	()
e)	Climbing one flight of stairs	()	()	()
f)	Bending, kneeling, or stooping	()	()	()
g)	Walking more than 1.6 kms (1 mile)	()	()	()
h)	Walking several blocks	()	()	()
i)	Walking one block	()	()	()
j)	Bathing or dressing yourself	()	()	()

4.ch During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as result of your physical health? (For each - check  $\sqrt{yes'}$  or 'no')

		Yes	No
a)	Cut down on the amount of time you spent on work or other activities	()	()
<b>b</b> )	Accomplished less than you would like	()	()
c)	Were limited in the kind of work or other activities	()	()
d)	Had difficulty performing work/other activities eg it took extra effort	()	()

Yes

()

No

()

()

5.ch	During the past 4 weeks, have you had any of the following problems with your work or other
	regular daily activities as result of any emotional problems (such as feeling depressed or
	anxious)? (For each - check $\sqrt{\text{'yes' or 'no'}}$

a)	Cut down on the amoun	of time you spend on work/other activities	s ()	()
----	-----------------------	--	------	----

- b) Accomplished less than you would like
- c) Didn't do your work/other activities as <u>carefully</u> as usual ()

6.ch

1	During the past	4 weeks, to what	extent has your physica	l health or emoti	onal problems	
	interfered with y	our normal social	activities with family, f	riends, neighbors	or groups?	
	(Circle one)					
	1	2	3	4	5	

-	-	-		-
Not at all	Slightly	Moderately	Quite a bit	Extremely

7.ch	How much bodily pain have you had during the past 4 weeks? (Please circle one)						
	1	2	3	4	5	6	
	None	Very mild	Mild	Moderate	Severe	Very severe	

8.ch During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)? (*Please circle one*)

1	2	3	4	3
Not at all	A little bit	Moderately	Quite a bit	Extremely

## 9.ch How much of the time during the past 4 weeks have you been feeling the following? For each - please check $\sqrt{}$ the one answer that comes closest to the way you have been feeling ...

	All of the	Most of the	A good bit of	Some of the	A little of the	None of the
	time	time	the time	time	time	time
Did you feel full of pep?	()	()	()	()	()	()
Have you been a very nervous person?	()	()	()	()	()	()
Have you felt so down in the dump	S					
that nothing could cheer you up?	()	()	()	()	()	()
Have you felt calm & peaceful?	()	()	()	()	()	()
Did you have a lot of energy?	()	()	()	()	()	()
Have you felt downhearted & blue?	()	()	()	()	()	()
Did you feel worn out?	()	()	()	()	()	()
Have you been a happy person?	()	()	()	()	()	()
Did you feel tired?	()	()	()	()	()	()
	Did you feel full of pep? Have you been a very nervous person? Have you felt so down in the dump that nothing could cheer you up? Have you felt calm & peaceful? Did you have a lot of energy? Have you felt downhearted & blue? Did you feel worn out? Have you been a happy person? Did you feel tired?	All of the time Did you feel full of pep? () Have you been a very nervous person? () Have you felt so down in the dumps that nothing could cheer you up? () Have you felt calm & peaceful? () Did you have a lot of energy? () Have you felt downhearted & blue? () Did you feel worn out? () Have you been a happy person? () Did you feel tired? ()	AllMost of the timeDid you feel full of pep?( )Have you been a very nervous person?( )Have you felt so down in the dumps that nothing could cheer you up?( )Have you felt calm & peaceful?( )Did you have a lot of energy?( )Have you felt downhearted & blue?( )Did you feel worn out?( )Have you been a happy person?( )Did you feel tired?( )	AllMostA good bit of timeDid you feel full of pep?()()Have you been a very nervous person?()()Have you felt so down in the dumps that nothing could cheer you up?()()Have you felt calm & peaceful?()()Did you have a lot of energy?()()Have you felt downhearted & blue?()()Did you feel worn out?()()U you feel tired?()()U you feel tired?()()	AllMostA goodSome of the timeof theof theof thebit ofof thetimetimetimetimetimetimeDid you feel full of pep?( )( )( )( )Have you been a very nervous person? ( )( )( )( )Have you felt so down in the dumpsthat nothing could cheer you up? ( )( )( )Have you felt calm & peaceful?( )( )( )Did you have a lot of energy?( )( )( )Have you felt downhearted & blue? ( )( )( )( )Did you feel worn out?( )( )( )( )Have you been a happy person?( )( )( )( )Did you feel tired?( )( )( )( )	All of the of the timeMost of the of the timeA good of the of the bit ofSome of the of the of the timeDid you feel full of pep?()()()()Have you been a very nervous person?()()()()Have you felt so down in the dumps that nothing could cheer you up?()()()()Have you felt calm & peaceful?()()()()()Did you have a lot of energy?()()()()()Have you felt downhearted & blue?()()()()()Did you feel worn out?()()()()()Did you feel tired?()()()()()

10.ch During the past 4 weeks, how much of the time has your physical health or emotional

problems interfered with your social activities (like visiting with friends, relatives, etc.)? (Circle one)

1	2	3	4	5
All of	Most of	Some of	A little of	None of
the time	the time	the time	the time	the time

11.ch How true or false is each of the following statements for you? (Put a check  $\sqrt{in the column}$ )

		Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a)	I seem to get sick a little easier					
	than other people	()	()	()	()	()
b)	I am as healthy as anyone I know	()	()	()	()	()
c)	I expect my health to get worse	()	()	()	()	()
d)	My health is excellent	()	()	()	()	()

## Part 3 – Questions about Quality of Life and Life Satisfaction

Here are some services and other things that affect people today. Please indicate how satisfied you are with each of them.

For each question - please circle one number between 1 - 7 using the following guide:

1 Very <u>Dis</u> satis	2 Somewhat sfied Dissatisfied	3 A little d Dissatisfied	4 Abo Bala Neu	out Even anced atral	5 A li Sati	ttle sfied	6 Somev Satisfi	what ed	7 Very <u>Sat</u> isfied	0 N/A
How sa	ntisfied are you wi	V <u>Dis</u> ith?	ery satisf	ied	B	alance	ed		Very <u>Sat</u> isfied	N/A
1.ss Yo	our home		1	2	3	4	5	6	7	0
2.ss Yo	our neighborhood a	s a place to live	1	2	3	4	5	6	7	0
3.ss Ye	our family relation	s, generally	1	2	3	4	5	6	7	0
4.ss Ye	our living partner (	eg spouse)	1	2	3	4	5	6	7	0
5ss He	ow you feel about 1	life as a whole	1	2	3	4	5	6	7	0
6.ss Y	our job		1	2	3	4	5	6	7	0
7.ss Y	our friendships		1	2	3	4	5	6	7	0
8.ss Y	our health		1	2	3	4	5	6	7	0

QUALITY OF LIF	Έ

9.ss	Your religion or spiritual fulfillment	1	2	3	4	5	6	7	0
10ss	Your overall quality of life	1	2	3	4	5	6	7	0
11.ss	Your financial security	1	2	3	4	5	6	7	0
12.ss	Your recreation activities	1	2	3	4	5	6	7	0
13.ss	Your self esteem	1	2	3	4	5	6	7	0
14.ss	Your overall standard of living	1	2	3	4	5	6	7	0

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15ss	<b>Considering your</b>	life as a whole,	how happy	would you say	you are?	(Please cir	cle <u>one</u> )
1	2	3	4	5	6	7	0
Very	Somewhat	A Little	Evenly	A Little	Somewhat	Very	NA
Unha	ppy Unhappy	Unhappy	Balanced	Нарру	Нарру	Happy	
Part 4 – Personal Information							

years old (Fill in your age in years) 1.cp Your present age:

2.cp	Are you:	a. Female	b. Male	(Circle one)
------	----------	-----------	---------	--------------

3.cp What is the highest level of schooling completed? (Circle one please)

ger i common
ersity
one please)

c.	Married	d.	Widowed
d.	Common-law partner	e.	Divorced
c.	Single	f.	Separated

#### What is your employment/productivity status? (Please circle all that apply) 5.cp.

a	. Employed	d.	Homemaker
ł	o. Own your own business	e.	Student
C	. Retired	f.	Volunteer

#### What was your last year's income level? (Circle one please) 6.cp

- a. Less than \$20,000 per year d. \$40,000 to 50,000 per year b. \$20,000 to \$30,000 per year
- c. \$30,000 to 40,000 per year
- e. \$50,000 to 60,000 per year
- f. over \$60,000 per year
- 7.cp How did you prepare to be a caregiver for a person who had a stroke? (Please circle all that apply)
  - a. Information from medical people eg therapist(s), doctor, nurse, social worker etc
  - b. Information from books, pamphlets, video, library, internet etc
  - c. Talked with other caregivers, family, friends, relatives, clergy

- d. From Stroke Club
- e. None of the above

 8.cp
 How prepared were you to be a caregiver for a stroke person? (Please circle one)

 a.
 b.
 c.
 d.

 Not prepared
 Somewhat prepared
 Mostly prepared
 Very prepared

- 9.cp Right now, how adjusted are you to your role of a caregiver? (Please fill in the blank with a number between 0% = not adjusted and 100% = fully adjusted) = \_\_\_\_%
- 10.cp Right now, do you attend a Stroke Club? c. No
  - d. Yes for how long? For \_\_\_\_\_ months. Or For \_\_\_\_\_ years. - how often do you attend club or other functions? = \_\_\_\_\_ times a year

 $\rightarrow$  This ends the questionnaire - please return it to your Stroke Club Coordinator.

Thank you very much, Anne-Marie Draper.

### Appendix G: Comments from Respondents

### COMMENTS FROM STROKE SURVIVOR QUESTIONNAIRES

- 8sa. Are you able to feed yourself?
  - Some respondents said "yes, if someone else cuts the meat up".
- 18sa. Are you able to reach past your nose?
  - Many respondents said 'yes, but only with my good arm", as stroke usually affects one side or other. Response options on the questionnaire only allowed for a blanket yes or no.
- 5sh. Have emotional problems interfered with your activities?
  - One respondent's caregiver noted that the emotional problems experienced by this stroke survivor were such that they are always cheerful with a positive attitude, regardless of the situation. This, of course, does not interfere, per se, but is still an emotional problem.
  - Another respondent's caregiver noted that the survivor in question was taking antidepressants. Therefore emotional problems were not interfering with their activities, but they were still present and wold affect the person if medication was note being administered.
- 7ss. Regarding satisfaction with friendships.
  - After a stroke you lose most friends and have to make new ones.
- 7sp. Which side of your body did the stroke affect?
  - In many cases, stroke did not affect one side or the other, it was a different type of strok (eg subarachnoid hemorrhage, mid-brainstem stroke)
- GENERAL
  - "Stroke patients are terrified by the current crisis of the health care system. They are afraid for the rest of their lives to have another one."

### COMMENT TO ANNE-MARIE DRAPER ON YOUR SURVEY

- I am grateful for the chance to make some of my views known, but I found your questionnaire (especially in the earlier questions) to be geared more to people who would be more commonly found living in care-homes NOT in the community, as you have specified. Also there was no room for "somewhat" or "partially" as answers see #1, 4, 5, 7, 9, Also you didn't ask about speech problems, or partial use (weak side).
- QUESTIONS on health. Do you just refer to stroke as being the 'bad' health? What about underlying/current problems?, that may cause fatique or inability to perform well? I AM VERY LIMITED BECAUSE OF MY INABILITY TO WALK QUICKLY OR TALK CLEARLY BUT I STILL CONSIDER MY HEALTH TO BE VERY GOOD!!
- Almost no one with strokes is able to work (for a living), so questions 8-11 in part 2 are hard to answer.
- I also think it is important to ask more questions about the stroke clubs and how they help us copy?!

### ADDENDUM TO QUESTIONNAIRE

Only questions 5,6 and 10 make any reference to the "emotional" aspect of stroke. This aspect is, I believe, far more important to both survivor and caregiver. In my case, I have mainly 'hidden' symptoms, that is, by looking at me, you would never know I had survived a stroke. My parts that don't work are invisible: eyes that don't see well, a brain that cannot calculate simple arithmetic, or react quickly to visual stimulus, so that for the past 13-years I am unable to drive a vehicle except in a farmer's field where the only damage I could do would be to run over a hay bale!

Your questions only alluded to depression, but did not touch on the periodic, but daily episodes of frustration at not being able to complete a task tat pre-stroke could be done in a finger-snap. This often leads to anger, which in turn may be directed at the nearest object or person.

The emotional stress on a couple is horrendous, particularly if the stroke survivor was the one did the major banking, financial dealings and the like. The other partneris often in the dark about such things and the stroke survivor is in no condition to complete those tasks OR teach the other what to do.

I hope you know and will recognize that EVERY person is effected in a different way by stroke. No two are alike and the recovery will take more or less effort than others.

### COMMENTS FORM CAREGIVER QUESTIONNAIRES

What is your relationship to the survivor?

- There was one granddaughter", however she only completed question 4 on the entire survey, so her data was not entered.

7cp. How did you prepare to be a caregiver?

- Preparation can come from previous life/work at least one respondent indicated that she is an RN by profession.
- One respondent commented that 'nothing can prepare you to be a 24/7 caregiver"
- One said it is "mostly instinct -just love them".

10cp. Do you attend a Stroke Club?

- One respondent said that they do not regularly, however they do attend special functions such as the annual Christmas party.
- Another used to but now cannot because of her work schedule.
- Another said that "there is a support group out here but no respite for me to be able to go".

### GENERAL

"These answers would have been totally different after he initial stroke and for at least 5 years!"

One question that was omitted was: There had been a <u>complete</u> change in personality – but has very <u>slowly</u> come back to his old self. <u>Still</u> very emotional. Will cry easily and very quickly to anger. Very demanding."

"I don't feel your questions reflect any insight into the role of the 24/7 caregiver. You completely give up your own identity as no real help is available!"

"I wonder why there are no questions about the loss of speech to the strokers."