Performance-based correlates of health-related quality of life in community-dwelling persons with stroke

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ABSTRACT

Health-related quality of life is diminished in persons with stroke as compared to age-matched, healthy individuals. Up to 27% of the stroke population have not been studied in terms of quality of life because they were unable to complete the necessary questionnaires or interviews. Performance-based measures have been suggested as a proxy to quality of life in those people, but the associations have not been evaluated. In order to determine the relationships between performance-based measures of physical function and health-related quality of life, a two-part cross-sectional study of 45 community-dwelling individuals 12 months post-stroke was conducted. The subjects' quality of life was assessed by telephone interview; as well, their physical function was evaluated at home by a physiotherapist. This study demonstrated a clear association between both mental and physical health-related quality of life and many performance-measured impairments and disabilities.

ABRÉGÉ

Les personnes ayant subi un accident cérébrovasculaire (ACV) ont une qualité de vie inférieure à celle des gens du même âge et en bonne santé. Cependant, jusqu'a 27 % de la population ayant subi un ACV n'a jamais été étudiée parce que leurs handicaps intellectuels et de communications ne leur permettent pas de répondre aux entrevues et aux questionnaires. La mesure de la capacité physique, executée par les patients eux-mêmes, a été suggerée comme indicatrice de la qualité de vie pour ces personnes. Toutefois, les associations entre ces variables n'ont pas encore été étudiés. Une étude transversale des 45 personnes ayant subi un ACV un an auparavant et demeurant dans la communauté a été effectuée dans le but de déterminer les associations entre les mesures de la capacité physique et la qualité de vie reliée à la santé, telle que rapportée par les sujets. La qualité de vie a été évaluée par entrevue téléphonique, et leur capacité physique a été évaluée au domicile par une physiothérapeute. Cette étude a demontrée une association évidente entre la qualité de vie reliée à la santé physique et psychologique, et certaines mesures de la capacité d'exécution des activités.

FOREWORD

By Sandra Kolber

I met Sandra Kolber while working as a replacement physiotherapist at the Jewish Rehabilitation Hospital, Laval, Quebec. She asked me the topic of my thesis and, in her own words, guffawed rudely when I told her it had to do with quality of life in stroke. She offered to write down some of her thoughts and personal experiences on the matter as a prologue to my thesis, and I enthusiastically accepted.

Sandra Kolber is an extremely distinguished lady: she is a member of the Order of Canada, has been awarded the Governor General's Award for her contribution to the Arts in Canada, is a published poet of two volumes, a mother and a grandmother. I am, indeed, honoured that she has taken an interest in this thesis, and am grateful to have her honest, heart-felt and thought-provoking prose grace these pages.

- S.E.M

It is ludicrous to speak of "stroke" without quantifying the extent of the event and its consequences. There are those who are stricken and survive, but with impairments and constant pain. There are those who are not permanently physically scarred. Indeed, I've read of a concert pianist who was stricken as he played and went on to complete the concert.

If it were possible to assign severity to stroke incidents, I assume it would have been done by now. How much more difficult, therefore, to describe how one's quality of life is affected by what I will call a catastrophic stroke. Actually, that is what the doctors called the stroke that felled me (and nearly killed me) several years ago.

"Quality of life" is amorphous and individual. There are no scientific standards that might be applied. If it is true, and I think it is, that no two strokes are the same, how could anyone assess the alteration in a life quality without having known a person, the life whose quality is discussed?

I'm only one of the thousands that could be described. It is true I had an outstanding quality of life, one of achievement, acknowledgment, recognition and reward. There are so many things I have lost by the paralysis with which I now live. If there is one word to best encompass them all, it is dignity. I lost independence, privacy, mobility, self-sufficiency. When one cannot care for herself in the most basic ways, dress, bathe, toilet - that person is flattened. When one needs constantly to be attended and assisted, she is naked, vulnerable, and self-despising. Masters of dehumanization must early have recognized this fact. That to strip a person of dignity is to degrade that person and debase him more quickly and viciously than to withhold from him food, drink, and other necessities.

As a woman who strove all her life for independence, it is a near-fatal blow (psychologically as well as physically) to be so reduced. "Ah," people say, "but how fortunate you are, that your mind and intellect have not been affected. It means that you are the same person you always were." This is simply not true. Because no one treats you the same way. Everyone stoops to converse with you when you are in a wheelchair and this patronizing stance pervades the way they see you and feel about you. They literally "talk down" to you. They speak about you in the third person when you are in the room as though you were not there. In a crowded elevator, you are at the eye level of everyone else's crotch. This begins to translate into how you feel about yourself and your skewed life.

Every time you want to go somewhere, elaborate research is necessary: Is there a ramp, an elevator? Someone must invariably be alerted to open a side-door or unlock an elevator. This leaves no room for spontaneity, for deciding at the last minute what the hell, let's just go somewhere, let's just do something. It inhibits your flexibility, your sense of "moment."

Every relationship you ever had is irrevocably altered. How could it not be? The pendulum has shifted position. You are not the only one who does not know how to handle the situation. A friend phones to offer solace. After stammering and spluttering for awhile, she says, "I don't know what's wrong with me. I'm usually extremely articulate." The upshot of the call is that it's you who must comfort your friend. Awkward, enervating, purposeless. And worse. "You're not the only one with problems, I have heard......" People get so flustered , they behave totally inappropriately. I once said I was becoming irritated at the behaviour of a good friend and an equally good friend told me, "I don't think you can afford to get angry at anybody right now." I certainly got the message but I didn't like it at all. "I know how you feel," I am constantly told. I restrain myself from answering, "How could you? Why should you?"

Still, the greatest insult is not being able to carry your grandchild around or play with her on the ground. This is intolerable. Profound fatigue permeates the body and the shoulder pain pulls and throbs and inundates the soul. No vehicle as cruel as the wheelchair has ever been invented.

One of the great joys in my life has been travel. No, not to beaches and resorts. Travel that is rough, exploratory, tentative. This is no longer an option. It is simply impossible to go where there are no facilities, to indulge the curiosity cultivated over a lifetime of "wanting to know" and to see.

I've had to refuse jobs I would have been thrilled to accept - the swearing in of new Canadian citizens is one. There is no way, however, I could accommodate to the choreography of the ceremony. So I have had to say no. So does life shrink and the extensions of living diminish.

ACKNOWLEDGMENTS

The past two very rewarding years have culminated in this thesis. I have benefited from the knowledge, past experience, and actual physical assistance of a number of people without whom this project would have been impossible.

My supervisors, Dr. Sharon Wood-Dauphinee and Dr. Nancy Mayo guided me sagely from the very beginning. They have been (to name just a few of their virtues) kind, wise, creative, practical, erudite, and above all - - positive! I was extremely fortunate to have had these two as supervisors, and I thank them sincerely for everything.

I thank Dr. David Gayton for his words of wisdom regarding the research proposal and thesis. Dr. Robert Côté and Lisa Wadep of the Montreal General Hospital provided invaluable assistance for the recruitment of subjects, and I thank them also.

Claudette Corrigan was (and remains) indispensable for her assistance with all the details of this research project. I thank her for all the help and advice she gave me, on tasks too numerous to list. I would also like to thank my fellow student, Carron Gordon, for her assistance in many areas. Most of all, I am grateful for her enthusiasm in helping me with the home assessments.

Jane Sutherland did, amongst other things, many of the telephone interviews, and conducted them thoroughly and compassionately. I am appreciative of her efforts as well. I would also like to thank Lina Petrulli, Penny Baylis, Lise Magnan, and again Claudette Corrigan for doing telephone interviews; and Penny Baylis and Ann-Jeanette Lu for accompanying me on occassional home visits.

I am grateful to Adrian Levy and Susan Scott for their guidance and assistance with the statistical analysis.

Forty-five patients participated in this project. I am indebted to them, and thank them profusely for their time and effort, as well as for the cookies, and coffees, and cakes!

I thank Sandra Kolber for writing the Foreword to this thesis. As I stated previously, it is an honour to have her poignant words grace these pages.

Jo-Anne Howe provided encouragement and advice to enter a Master's program in the first place, and to her I am ever grateful.

I acknowledge the financial assistance received from the Royal Canadian Legion Fellowship in Gerontology and le Reseau provincial en réadaptation-adaptation.

I'm certain that I benefited from the kindness and knowledge of many other people along the way, and I thank anyone whose name has been inadvertently missed.

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1.0 INTRODUCTION AND RATIONALE

Each year in Quebec roughly eight thousand people sustain a stroke (Mayo, Goldberg, et al., 1991), and between 50% and 70% are alive one year after the event (Asberg and Parrow, 1991; Bonita et al., 1984; Gross et al., 1984; Mayo, 1993; Sivenius et al., 1985). Many of those people are living with the impairments and disabilities that are the sequelae of stroke. One-half to one-third are partially or completely dependent in their basic activities of daily living (ADL) (Asberg and Parrow, 1991; Bonita et al., 1984; Gross et al., 1984; Mayo, 1993; Sivenius et al., 1985); many are unable to ambulate (Dove et al., 1984; Heinemann et al., 1987; Wade et al., 1987), or live with a diversity of other disablements. As well, the health-related quality of life of these individuals is often less than that of a healthy individual of the same age (Angeleri et al., 1993; Åström, Adolfsson, et al., 1992; Åström, Asplund, Åström, 1992; Ebrahim et al., 1986; Viitanen et al., 1988).

Self-reported health, or health-related quality of life, is a clear predictor of mortality (Idler et al., 1990; Mossey et al., 1982; Roos and Havens, 1991; Tsuji et al., 1994), and as such is an important area of research in chronic diseases. While it is established that health-related quality of life is often diminished post-stroke, the specific disablements most strongly associated with this decline are unknown.

Physical and occupational therapists are frequently involved with the treatment of stroke patients, either in acute care, in rehabilitation settings or at home. Their treatments, at one level, are aimed at reducing impairments such as spasticity, weakness, diminished balance and coordination, sensory loss and lack of voluntary motor control. In more global terms therapy is directed towards promoting functional performance and reducing the patient's overall disability. Therapists, as do other health care professionals, often describe their overall treatment goal as improvement of the patient's quality of life. Despite being described as a main objective of rehabilitation, quality of life is rarely used to evaluate the outcome of patients with stroke (Wood-Dauphinee et al., 1994). This may be because we, as rehabilitation clinicians, are making an assumption that reducing impairments and disabilities has a positive impact on quality of life . While this assumption is credible, in the case of stroke patients there is minimal evidence to support it. In the few studies that examined the impact of impairments and disabilities on quality of life, a substantial proportion of stroke survivors who reported a decreased quality of life were also classified as independent or "normal" in activities of daily living (ADL) (Ahlsio et al., 1984; Åström, Adolfsson, et al., 1992; Lawrence and Christie, 1979; Viitanen et al., 1988). While there is considerable evidence to suggest that the stroke survivor's quality of life is worse than that of a healthy individual of the same age, the specific implicating factors are largely unknown.

Measurement of health-related quality of life is difficult in those persons with intellectual or communication deficits. In most studies, only communicative individuals are examined . Thus, roughly 20% of individuals with stroke are never studied, and presumably these are some of the most severely disabled people. While proxies are sometimes used (Åström, Asplund et al., 1992; Åström, Adolfsson, et al., 1992), they are not the ideal way to measure the quality of life of people unable to complete questionnaires or interviews (Mackenzie, 1986; Pierre et al.,1995). Patrick (1992) recently suggested that performance-based measures be examined as proxies for quality of life in persons with intellectual limitations.

If the ultimate goal is to discharge stroke survivors to the community with a good quality of life, then health care providers must treat the specific sequelae of stroke that are contributing factors. Furthermore, they must be able to gauge quality of life in all patients, not only those with sound communication skills. Thus, it is important to attempt to understand the relationships between observable attributes of a patient's daily function and his or her quality of life. This study set out to examine the relationships between performance-based measures of physical function and health-related quality of life as reported by community dwelling persons with stroke.

In Chapter Two, current knowledge about stroke and quality of life is summarized. Background material is provided on stroke and quality of life as distinct areas. More specific literature pertaining to the quality of life of persons with stroke is then reviewed, including information on the performance-based correlates of quality of life.

In Chapter Three, the objective of the study is summarized. Specific study questions and their hypotheses are then formally stated.

The methodology chosen to answer the study questions is discussed, in Chapter Four. The study design and study population are described in the initial sections. The instruments chosen to measure the performance-based variables and the health-related quality of life of persons with stroke are outlined in terms of content and psychometric properties. In the same chapter, methods of data analysis and the treatment of ethical issues are summarized.

The results of the study are given in Chapter Five. The characteristics of the study sample are delineated, and compared to the study population where possible. Descriptive statistics are given for the outcomes, mental and physical health-related quality of life, and for the performance measures. As well, associations between the performance measures and the outcomes are described and explained.

The final chapter of this thesis seeks to utilize the results of the study to answer the questions posed in Chapter Three. As well, it addresses some interesting findings and comments on the place of this research in relation to previously published literature pertaining to the quality of life of stroke patients. Chapter Six also discusses some limitations of this study, and their possible effects on the results. Finally, the contributions of the project are presented, and ideas for future research are put forth.

2.0 LITERATURE REVIEW

2.1 Stroke and Its Sequelae

Stroke is defined by the World Health Organization (1980) as "rapidly developing clinical signs of focal (or sometimes global) disturbance of cerebral function lasting more than 24 hours or leading to death with no apparent cause other than that of vascular origin." It is either ischemic or hemorrhagic in nature, and its symptoms and outcome vary according to the size, type, and location of the lesion. The most notable characteristic of stroke is sudden hemiparalysis or hemiparesis. As well, dysphasia or aphasia, memory impairment, altered sensation, difficulty swallowing, or incontinence may be present. Stroke occurs frequently, and leads to death in about one third of cases. Many of those who survive live with chronic disablements.

Ischemia and resulting tissue infarction may result from arterial occlusion due to atherosclerosis, thrombus or embolus, or systemic hypotension, or by conditions such as thrombocytosis, which cause blood constituents to be too viscous to be propelled through the arteries. As little as five minutes of interrupted blood flow may cause permanent cerebral tissue damage (Toole, 1984). Ischemic stroke may occur anywhere in the cerebral arterial system. Signs and symptoms vary depending on the specific location. Table 2.1 describes various syndromes associated with specific vascular lesions.

Intracerebral hemorrhage is the result of a ruptured vessel, often a microaneurysm caused by chronic arterial hypertension. Five to 20 % of strokes are hemorrhagic (Bogousslavsky et al., 1988; Humphrey, 1994; Mayo et al., 1989), and approximately half of those are fatal.

The overall incidence rate of stroke in Quebec is estimated to be 151 per 100,000 population (Mayo, Goldberg, et al., 1991). That places Quebec roughly in the middle of recent world-wide figures from a World Health Organization (WHO) study; age-standardized incidence rates per 100,000 varied from 101 to 285 for men and 47 to 198 for women (Thorvaldsen et al., 1995). The rate of stroke increases with age, occurring at a rate of three per 1000 persons between the ages of 50 and 64 years as compared to 12 per 1000 between the ages of 65 and 74 years and 25 per 1000 for persons over the age of 80 years (Mayo, et al., 1991a). Death occurs frequently after a stroke. The case fatality rates 28 days post-stroke, for the 16 European and two Asian countries in the WHO project, ranged from 15% to 49% for men and from 18% to 57% among women (Thorvaldesen et al., 1995). In Montreal, Canada, the in-hospital case-fatality rate from stroke has been estimated at 21% (Mayo et al, 1989). Most deaths from stroke occur in the first month after the event (Mayo, 1993).

Table 2.1
Vascular syndromes. (Brust, 1984)

Artery	Associated Syndrome
Main division, middle cerebral artery	hemiplegia, hemianesthesia, hemianopia, aphasia or denial and hemineglect (DHN)
Upper division, MCA	hemiparesis & sensory loss - arm&face>leg, Broca's aphasia, or DHN
Lower division, MCA	Wernicke's aphasia or DHN
Penetrating artery, MCA	pure motor hemiparesis
Common carotid artery	asymptomatic
Internal carotid artery	ipsilateral blindness, contralateral hemiparesis and hemianesthesia, hemianopia, aphasia, or DHN
Anterior cerebral artery	hemiparesis and sensory loss leg>arm, impaired responsiveness (abulia or akinetic mutism, especially if bilateral), left-sided ideomotor apraxia or tactile anomia
Cortical, unilateral, posterior cerebral artery	isolated hemianopia, alexia, or colour anomia
Cortical, bilateral, PCA	cerebral blindness
Thalamic, PCA	pure sensory stroke, may leave anesthesia dolorosa + spontaneous pain
Subthalamic, PCA	hemiballism
Bilateral inferior temporal lobe, PCA	amnesia
Midbrain, PCA	oculomotor palsy and other eye movement abnormalities
Vertebrobasilar signs	bilateral long tract signs, dissociated sensory loss, cerebellar signs, stupor or coma, nystagmus, involvement of cranial nerves not usually affected.

MCA= middle cerebral artery; PCA=posterior cerebral artery; DHN=denial and hemineglect.

Stroke is the third leading cause of death in Canada, following cardiovascular disease and malignant neoplasms (Statistics Canada, 1990). However, 50 % to 70% of people who have a stroke are alive one year following the event (Asberg and Parrow, 1991; Bonita et al., 1984; Gross et al., 1984; Mayo, 1993; Sivenius et al., 1985). Tragically, many of these individuals suffer the physical, psychological, and social sequelae of the disease. Improvements in post-stroke survival have been reported by various authors (Howard et al., 1989; Terént, 1988). Most recently, May, Casper, Croft and Giles (1994) reported an improvement in survival from 1985 to 1989, particularly in hemorrhagic strokes. Thus, the number of people living with residual impairments and disabilities may also be on the rise.

Most physical recovery occurs in the first few months following the stroke (Jørgensen et al., 1995c; Mayo, Korner-Bitensky, et al., 1991; Reding and Potes, 1988), but latent recovery may continue for months or years (Humphrey, 1994; Scmidt et al., 1988). More than 1100 patients with acute stroke were followed to six months post-event in the Copenhagen Stroke Study (Jørgensen et al., 1995c). The authors reported that functional recovery was completed within 12.5 weeks for 95% of patients, and that neurological recovery preceded functional recovery by about two weeks. Even after neurological recovery ceases, the individual's performance status may improve as he or she adapts physically, socially, and psychologically.

Some of the most common sequelae of stroke (refer to Table 2.2) are in the areas of self care, locomotion, motor control, bladder continence, psychosocial function, communication, perception, and cognition (Barer, 1989; Gowland, 1982; Gresham et al., 1979; Jørgensen et al., 1995a, 1995b; Labi et al., 1980; Reding and Potes, 1988; Skilbeck et al., 1983; Tatemichi et al., 1994; Wade and Hewer, 1987a&b; Wade et. al., 1987; Wade et al., 1988a&b). Decreased ability to care for oneself is the most frequent consequence. Moderate or complete assistance with ADL is required by one-half to one-third of people six months post-stroke (Andrews et al., 1984; Bonita and Beaglehole, 1988; Jørgensen et al., 1995b; Wade and Hewer, 1987b). Although half to three-quarters of people who survive a stroke are able to walk independently[1] within a few months (Dove et al., 1984; Heinemann et al., 1987; Jørgensen et al., 1995a; Wade et al., 1987), less than 20% walk at normal speed (Wade et al., 1987).

In terms of motor recovery, the lower extremity fares better than the upper. Gowland (1982) reported that one third of stroke rehabilitation patients have no upper extremity recovery upon discharge, whereas only 10% have severe lower extremity motor loss. Results from the recently published Copenhagen Stroke Study indicated that 11% of six month survivors have severe neurological deficits, 11% have moderate deficits, and 78% have no or mild deficits (Jørgensen et al., 1995b). The authors did not report on differences between the upper and lower limb.

The problems of perceptual impairment, swallowing dysfunction, and incontinence are not commonly seen after three months, however their initial presence is associated with higher rates of death and dependency. Fullerton, McSherry, and Stout (1986) found initial visual hemi-neglect in approximately 30% of patients, but in a separate prospective study by Wade and colleagues (1988b) only three per cent demonstrated clear neglect by six months post-stroke. Presence of visual hemi-neglect at the time of stroke is closely correlated to a poor six month outcome, as measured by death, and dependence in activities of daily living (Fullerton et al., 1986). Wade and Hewer (1987a) estimated about 40% of the stroke population had initial difficulty swallowing, but that less than two per cent of six month survivors had such an impairment. Swallowing dysfunction was associated with a higher case fatality rate. Six months after stroke, only 11 % to 14% suffer bladder incontinence, as compared to more than half on the first day (Barer, 1989; Wade and Hewer, 1987b). However, initial incontinence, as with swallowing impairment and presence of visual hemi-neglect, is a major prognostic indicator of poor outcome (Wade and Hewer, 1987b).

Psychosocial and cognitive function are also affected post-stroke. Cognitive

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[1] With or without an assistive device.

impairment was found in 35 % of patients three months post-stroke, compared to only four per cent of controls (Tatemichi et al., 1994). These individuals had a higher mortality than other stroke patients. As many as one quarter of stroke survivors reported at least one major symptom of depression up to three years post-stroke (Åström, Asplund and Åström, 1992). Angeleri et al. (1993) discovered increased depression and diminished social activity scores in individuals at least one year post stroke as compared to controls. Persons with stroke have been reported to have only half the number of opportunities as age-matched controls for socialization outside the home (Labi et al., 1980). Speech disturbances occur frequently at the time of stroke, however only 10% persist (Jerntorp and Berglund, 1992; Scmidt et al., 1988).

To summarize typical stroke recovery, let us imagine the one-year outcomes of a group of one hundred individuals who had a stroke today.[2] About 35 of them would probably die before the end of the year, but most of the rest would show steady improvement in their functional status. Fifty people would be living in their own homes, and, of those, 40 would be completely or mostly independent with their activities of daily living. The remaining 15 would reside in long-term care institutions. It would be expected that as many as 20 people would be non-ambulatory by the end of one year, but, at the other end of the scale, about 15 would be walking at normal speed. The majority, 30 individuals, would be walking slowly and possibly with an assistive device. Those people who died, who live in a long-term care facility, or who live at home with at least moderate dependency in activities of daily living are more likely to: have sensory deficits (Reding and Potes, 1988), be older (Gowland, 1982), have several comorbid conditions (Dove et al., 1984), have decreased comprehension , be depressed, and to have had initial bladder incontinence, perceptual, or swallowing difficulties.

Many people survive stroke and return to community living with some form of

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[2] This scenario is fabricated, based on proportion estimates from the literature reviewed in the previous section.

disablement. De Pedro-Cuesta and colleagues (1993) estimated that nearly one out of every 1000 community-dwelling people in Sweden had residual effects of a stroke, and of those, three-quarters desired further therapy.

Considering the diversity and chronicity of stroke sequelae, a decrease in quality of life in this population would not be unexpected. Indeed, numerous authors have found evidence of such a problem. The remaining sections of the literature review will describe quality of life, and, more specifically, the quality of life in people with stroke.

Table 2.2

Literature pertaining to the sequelae of stroke

Author[a]	Subjects	Design	Outcomes	Measures	Selected Results
Gresham, 1979	148 long-term strokes, 148 comparisons	Survey, >6m (Framingham)	ADL	Donaldson ADL form	worse than controls
			Handicap	Author's questionnaire	worse than controls for all of 9 dimensions
Gowland, 1982	229 strokes admitted to rehabilitation centre	pros. cohort to discharge	Motor recovery arm & leg	Brunnstrom stages	75% less than stage 5 arm
			Gait	3-point severity scale	52%unable or require supervision
			Gross motor performance	16 tasks, 6 grades	41% dependent (<grade 5)
Wade & Hewer, 1987a	976 strokes	0-6m, pros. cohort	Motor loss	4-point severity scale	arm: 12%severe, 6%mod.,27% mild,55% none; leg: 7% severe, 29% mod, 57% none.
			Swallowing	4-point severity scale	<2% had problems at 6m, but had a higher case fatality rate
Wade & Hewer 1987b	976 strokes	0-6m, pros. cohort	ADL	Barthel Index	45% of survivors independent at 6m
Wade et al., 1987	60 strokes	0-3m, pros. cohort	Gait	gait speed amount of assistance	3 ms-40% N, 33%<N, 25% unable 62% indep, 13% walking aid

Table 2.2 continues on the following page. Legend is at the end.

Table 2.2 (continued)

Literature pertaining to the sequelae of stroke

Author[a]	Subjects	Design	Outcomes	Measures	Selected Results
Wade, 1988b	62 strokes	0-3m, pros. cohort	3 aspects of cognition:		
			Visual neglect	Rivermead P.A.	50 assessed, only 3% had clear neglect
			Attention span	Wechsler's digit span	20% improved @ 3 months
			Verbal recall	AVLT	44 assessed, 20% improved from 0m- 3m
Bonita, 1988	680 strokes		Motor Deficit	4-point severity scale	39%none,36%mild,11%mod.,14%severe
Reding, 1988	95 strokes admitted to rehabilitation centre	0-6m, pros. cohort	ADL	Barthel Index	only motor deficit, mean Barthel = 81 motor+sensory, mean Barthel=67 motor+sensory+visual, mean Barthel=52
Barer, 1989	362 strokes	0-6m, pros. cohort	Urinary incontinence	3-point severity scale	58%incont.@0m, 40%of those dead @6m 14% survivors incont. @ 6m.
Jorgensen, 1995a	804 consecutive strokes	Pros. cohort to discharge	Gait	amount of assistance	by discharge 21% died, 18% unable, 11% with assist, 50% indep (includes with aid)
			Place of discharge	3-point severity scale	21% died, 15%NH, 64% home
Jorgensen, 1995b	1197 strokes	0-6m, pros. cohort	Neurological deficits	Scandinavian Stroke Scale	11% severe deficit, 11% moderate, 78% mild or no deficit
			ADL disability	Barthel Index	20%<45, 8%<75, 26%<95, 46%=100

a=in most cases, only the first author is given; m=months; ADL=activities of daily living; pros.= prospective; indep.=independent; mod.= moderate; N=normal; NH=nursing home; @=at; Rivermead P.A. = Rivermead Perceptual Assessment (Bhavnani G. et al., 1983.); Wechsler's Digit Span (Wechsler D, 1945.); AVLT=Rey Auditory-Verbal Learning Test (Lezak, 1976.); Brunnstrom stages (Brunnstrom S, 1970); Donaldson ADL form (Donaldson et al, 1973); Barthel Index (Mahoney and Barthel, 1965); Scandinavian Stroke Scale (Lindenstrøm et al., 1991).

2.2 Quality of Life and its Measurement

Quality of life refers to a person's feelings of satisfaction and worth about his or her life circumstances. Flanagan (1982) identified material comforts, occupation, health and safety, recreation, education, family relationships and socialization as factors contributing to quality of life. Although all of the components play an important role in determining an individual's quality of life, many of them are beyond the realm of health care (Guyatt et al., 1989; Ware, 1984). Health care researchers and clinicians thus focus their attention specifically on health-related quality of life, or health status.

Over the past decade and a half, much effort has been devoted to conceptualizing and quantifying health-related quality of life. While there is some disagreement as to a specific definition, a number of well-developed measurement tools with good psychometric properties have evolved. In the following paragraphs, health-related quality of life is defined. As well, its importance and approaches to measuring it are discussed.

Quality of life is not easily defined. It is a complex, intangible concept that evokes different images and ideas in those who encounter the term. Initially, quality of life was seen to be mediated by material well-being, but later came to be viewed as one's subjective satisfaction with his or her circumstances (McDowell and Newell, 1987). Health-related quality of life is depicted by Schipper, Clinch and Powell (in Spilker,1990) as an outcome that seeks to "describe the overall results of our diagnostic and treatment efforts in a way that makes sense to both patients and health professionals." They offer the following broad definition:

> "'Quality of life' represents the functional effect of an illness and its consequent therapy upon a patient, as perceived by the patient. Four broad domains contribute to the overall effect: physical and occupational function; psychological state; social interaction; and somatic sensation."

Patient perception is an essential component of the definition. Quality of life assessments require input from patients in order to be accurate, as the correlation between health-care provider and patient perceptions is often low (Slevin et al., 1988; Wood-Dauphinee et al., 1988). Sprangers and Aaronson (1992) reviewed the literature comparing health care providers' and significant others' evaluations of quality of life to the patients' own assessments. The literature revealed that both the health care providers and significant others tended to underestimate quality of life. Epstein et al. (1989) cautioned that using proxies intermingled with subjects to measure health status could lead to biased results. Due to the subjective nature of the concept, the patient is in the best position to judge the state of his or her life.

The definition also refers to four broad domains. These have been classified slightly differently by various authors, however the important idea is that health-related quality of life is multi-dimensional. Health, which is defined by the World Health Organization (1980) as "a state of complete *physical, mental, and social well-being* and not merely the absence of disease or infirmity," itself has three broad domains. These, at least, must be incorporated in the notion of health-related quality of life.

Health-related quality of life is important both as an outcome measure and as an entity of its own. Spilker (1990) gives numerous reasons for studying quality of life including the following: 1) to improve the quality of treatment; 2) to differentiate between two therapies with marginal differences in survival or morbidity; 3) to compare outcomes of different treatment modalities; 4) to improve the allocation of health care resources. In these cases, quality of life is seen primarily as an outcome measure used to describe and quantify overall treatments effects. However, quality of life in itself is useful. Most health care providers would say that their ultimate goal is improving the patient's quality of life. Furthermore, evidence is mounting that quality of life has prognostic value. Numerous studies (Idler et al., 1990; Mossey et al., 1982; Roos and Havens, 1991; Tsuji et al., 1994) have found self-reported health status to be an important predictor of mortality. A large, prospective study in Japan found that fair and poor self-rated health, adjusted for age-group and sex, were strongly associated with *stroke* mortality in particular; the risk ratios were estimated at 4.0 and 15.5 respectively (Tsuji et al., 1994).

There has been some discussion as to what constitutes a quality-of-life measure and what constitutes a general health measure. While some authors consider them to be the same or similar constructs (de Haan, Aaronson et al., 1993), others (Hornquist, 1982; McDowell and Newell, 1987; Nydevik and Hulter-Asberg, 1992) feel that in order to be a quality of life measure, the scale must account for global aspects of life, such as life satisfaction.[3] Certainly there is overlap, and it has become popular to designate both types of measures as "health-related quality of life" or "health status" instruments. Regardless of name, considerable evidence exists that the content is multi-dimensional and that the measures should reflect this (McDowell and Newell, 1987). Quality of life can and has been estimated with single item scales; for example, the patient is asked to rate his or her health on a scale from 0 to 100, as described by Tsevat and colleagues (1991). Multi-dimensional scales, however, are more reliable, define health levels more distinctly, and represent the content of health perceptions better than unidimensional measures (McHorney et al., 1992). Mangione et al. (1993) found that the relative contribution of specific domains to overall quality of life varied between young versus old patient populations further emphasizing the importance of multi-dimensionality when assessing health status. Also, as mentioned previously, correlations between health-care professionals' assessments of quality of life and the patient's own assessment are low. Thus, in addition to being psychometrically sound, a comprehensive measure of health-related quality of life comprises multiple dimensions, a section on global quality of life, and is rated by the patient.

Several health-related quality of life measures exist, but the only three that appear to have been used in past stroke studies are the Sickness Impact Profile (SIP) (Bergner et al., 1981), the Nottingham Health Profile (NHP) (Hunt et al., 1980), and the 36-item Short

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[3] Life satisfaction is a component of quality of life, however on its own it is of limited value in evaluative research (Bowling, 1991).

Form Health Survey (SF-36) (Ware and Sherbourne, 1992). The SIP is a 136-item measure divided into 12 categories: ambulation, mobility, body care and movement, social interaction, alertness behaviour, emotional behaviour, communication, sleep and rest, eating, work, home management, recreation and pastimes. The respondent marks the statements that are related to health and reflect his or her situation of the day. Scores range from zero to 100, with increasing numbers reflecting increased sickness impact or decreased health status. The first part of the NHP has 38 questions on mobility, energy, pain, emotional reactions, sleep and social isolation. The second part has questions on seven life areas and refers to the effects of health on them. The SF-36 consists of 35 items that contribute to eight health dimensions: limitations in physical function, limitations in usual role due to physical health, limitations in usual role due to emotional health, mental health, bodily pain, vitality, general health perceptions, and social functioning. Each of the eight dimensions is transformed to a score out of 100, with lower numbers indicating poorer quality of life. The 36th item is a health transition indicator.

De Haan, Aaronson et al. (1993) recently reviewed a number of quality of life instruments for use in stroke outcomes studies. They reported that the SIP has substantial internal reliability, construct validity, and moderate test-retest reliability on an item level, and moderate responsiveness. Other investigators have noted that this instrument may be more sensitive to deterioration than to improvement (Mackenzie et al., 1986). Schuling et al. (1993) also found that the SIP was unresponsive to changes in ADL status, and thus may not be the scale of choice for stroke outcomes research. The NHP has moderate to substantial test-retest reliability, substantial construct validity, but questionable responsiveness (de Haan, Aaronson et al., 1993). The SF-36 has been rigorously tested and has demonstrated good internal and test-retest reliability (Brazier et al., 1992; McHorney et al., 1992), validity (McHorney et al., 1992, 1993), and responsiveness (Katz et al., 1992).

Besides psychometric properties, respondent burden must be taken into account when considering a quality-of-life instrument. There are trade-offs between long, comprehensive instruments and those which are short and easy to administer (McHorney et al., 1993). The NHP consists of 45 items compared to the SIP's 136. The SF-36, as its title implies, has 36 items. It has demonstrated good criterion and construct validity (Ware and Sherbourne, 1992). Short-form multi-item scales such as this offer a good compromise between practical considerations (responder burden of long-form scales) and psychometric standards (decreased reliability of single item scales) particularly when being used to measure general health perceptions (McHorney et al., 1992).

2.3 Studies on the Quality of Life in Stroke

Over the past decade, a number of investigators have examined the effect of stroke on quality of life and have largely concluded that there is a decrease following the insult (Ahlsio et al., 1984; Angeleri et al., 1993; Åström, Adolfsson et al., 1992; Åström, Asplund, Åström, 1992; Ebrahim et al., 1986; Johansson et al., 1992; Kappelle et al., 1994; Lawrence and Christie, 1979; Niemi et al., 1988; Nydevik and Hulter-Asberg, 1991, 1992; Osberg et al., 1988; Viitanen et al., 1988). These studies were selected for review either because they had quality of life as a stated outcome or because they used a standardized instrument to measure the construct (SIP, NHP, or SF-36). Some investigators chose inadequate instruments, thus have not wholly or accurately measured quality of life. Such studies have been reviewed nonetheless, due to the paucity of pertinent literature and in light of the evolving theoretical basis of health-related quality of life. The studies have differed greatly from each other in terms of measurement of quality of life, choice of specific outcomes and their measurement, design and statistical approaches (see Table 2.3). A brief overview of the literature is provided below.

Stroke survivors have a lower quality of life compared to the general population of the same age (Angeleri et al., 1993; Åström, Adolfsson, et al., 1992; Åström, Asplund, Åström, 1992; Ebrahim et al., 1986; Viitanen et al., 1988). Viitanen et al. measured quality of life cross-sectionally in 62 people four to six years post-stroke using a seven item, six point Likert scale. Fifty-eight per cent of the individuals living with the sequelae of stroke reported that they were very satisfied or satisfied with their life in general, compared to 86% of a comparison group from the healthy population. None of the comparison group reported being dissatisfied or very dissatisfied, whereas 18% of the stroke survivors provided these ratings. At least one aspect of quality of life had decreased for 61% of the patients. Ebrahim et al. evaluated 153 communicative stroke survivors' quality of life at one and six months post stroke using the Nottingham Health Profile. The persons with stroke had worse scores than the controls on many of the dimensions, including energy, pain, emotion, isolation, and mobility. Åström and colleagues (Åström, Adolfsson, et al., 1992; Åström, Asplund, Åström, 1992) found that those individuals who had suffered a stroke had more psychiatric symptoms, lower functional ability, and reduced life satisfaction as compared to the general elderly population. In a study by Angeleri and colleagues (1993), quality of life was considered to be a composite of four scales designed to measure ADL, depression, social dysfunction, and family stress. The 180 subjects, all at least one year post-stroke, scored lower in all domains than age-matched controls.

Several investigators have compared quality of life post-stroke to pre-stroke (Johansson et al., 1992; Lawrence and Christie, 1979; Niemi et al., 1988; Viitanen, et al., 1988), and all found that the majority of survivors do not return to their pre-stroke levels.

Osberg et al. (1988) used multivariate analysis techniques to find predictors of three long-term outcomes post stroke, including life satisfaction. They determined that subjects with low life satisfaction at 12 months were more severely ill in the post-acute period, had lower life satisfaction at one month post discharge, and had less social support.

Changes in quality of life over time have also been documented. Nydevik and Hulter-Asberg (1992) found an a decrease in quality of life as measured by the SIP at three years post-stroke as compared to six to nine months post-stroke whereas Åström, Asplund and Åström (1992) estimated that life satisfaction at one year remained the same at three years. The different findings could be due to timing of the initial assessment, or because the SIP may be more responsive to deterioration than other scales (Mackenzie et al., 1986).

A prospective follow-up of young people with stroke (aged 15 to 45 years) was conducted by Kappelle et al. (1994). These investigators used parts of the SF-36 to assess quality of life and determined that approximately half of the sample reported moderate or poor physical and social functioning, and that about one-third reported moderate or poor quality of life due to emotional problems.

Measurement of quality of life in these studies was frequently not ideal. In many cases, unrecognized or unvalidated measures were used. Viitanen (1988), Niemi (1988), Angeleri (1993) and colleagues opted for home-made scales with unknown psychometric properties. Ahlsio (1984) used a single-item visual analog scale, currently considered inadequate for quality of life assessments. Nydevik and Hulter-Asberg (1991, 1992) used the SIP, which has been found to be unresponsive to improvements in activities of daily living and, thus, is not the instrument of choice for stroke outcomes research (Schuling et al., 1993). Only parts of the SF-36 were used by Kappelle et al. (1994), suggesting that important quality of life domains were not measured, including general health perception.

Table 2.3

Literature pertaining to the quality of life of stroke patients

Author[a]	Subjects	Design	Outcomes	Measures	Statistics	Excluded
Lawrence, 1979	45 strokes	Survey, 3 yrs	Physical disability Global QL	Rankin Single item. 3 grades	Univariate	Unknown
Ahlsio, 1984	96 strokes &TIA's	Pros. cohort, 0-2 yrs	Global QL ADL	VAS Katz	Univariate	Unknown
Ebrahim, 1986	153 strokes 200 comparisons	Pros. cohort, 1-6 m.	QL Physical disability	NHP Author's scale	Univariate	~15%
Niemi, 1988	46 young (<65) strokes	Survey, 4 yrs	QL Cognitive function Neurological deficits	Author's quest. WAIS, WMS Neurologist's assess	Multivariate	~11%
Osberg, 1988	89 strokes and TIA's	Survey, 1 yr	12 month outcome Life satisfaction Medical charges	* Single item, 5 grades **	Multivariate	Unknown
Viitanen, 1988	62 strokes	Survey, 4-6 yrs	QL	Author's scale	Univariate	~27%
Nydevik, 1991	57 strokes	Pros. cohort, 0-9 m	ADL	Katz	Univariate	~20%
Åström, Adolfsson, 1992	76 strokes comparison group	Pros. cohort, 0-3 m.	ADL Life satisfaction	Katz Author's quest.	Univariate	proxies
Åström, Asplund, 1992	50 strokes comparison group	Pros. cohort, 0-3 yrs	ADL Depression Life satisfaction	Katz DSM-III Author's quest.	Univariate	proxies

Table 2.3 continues on the next page. Legend appears at the end.

Table 2.3 (continued)

Literature pertaining to the quality of life of stroke patients

Author[a]	Subjects	Design	Outcomes	Measures	Statistics	Excluded
Johansson, 1992	225 strokes	Pros. cohort, 0-1 yr	ADL QL	Author's scale NHP		Unknown ?~35%
Nydevik, 1992	36 strokes	Pros. cohort, 0-3 yrs.	ADL Sickness Impact	Katz SIP	Univariate	~20%
Angeleri, 1993	180 strokes 167 comparisons	Survey, 1-16 yrs	ADL Depression Social Dysfunction Family Stress	NUDS* Beck* Linn* Greene*	Univariate & Multivariate	~17% aphasic but included?
Kappelle, 1994	296 young strokes (15 - 45 yrs)	Retr. cohort , 2-16 yrs	ADL QL Neurological deficits Handicap	Barthel Index SF-36 NIHSS, MMSE GOS	Mostly univariate	Unknown ? proxies

a=in most cases, only the first author is given. TIA = transient ischaemic attack; Pros. = prospective; Retr. = retrospective; QQL = quality of life; comp. = comparison group; VAS = visual analogue scale; NHP = Nottingham Health Profile (Hunt et al., 1980); quest. = questionnaire; ADL = activities of daily living; yrs = years; m = months; * = composite outcome comprised of survival, place of residence, and Barthel Index (Mahoney and Barthel, 1965) score; ** = all out-patient and rehospitalization costs incurred; SIP = Sickness Impact Profile (Bergner et al., 1981); WAIS = Weshsler Adult Intelligence Scale (Wechsler, 1945); WMS = Wechsler Memory Scale (Wechsler, 1945); DSM-III = Diagnostic and Statistical Manual of Mental Disorders, ed. 3 (American Psychiatric Association Committee on Nomenclature and Statistics, 1980); Rankin Scale (Rankin, 1957); Katz Index of ADL (Katz et al., 1963); NUDS= Northwestern University Disability Scale. NIHSS = National Institutes of Health stroke scale (Brott et al., 1989); MMSE = Mini-Mental State Examination (Folstein et al., 1975); GOS = Glasgow Outcome Scale (Jennet and Bond, 1975) ; * - unreferenced in Angeleri et al., 1993; # - Excluded because of cognitive or communication problems rendering patient unable to complete questionnaire or interview.

Ten per cent to 27% of the individuals with stroke could not complete quality-of-life interviews (Ahlsio et al., 1984; Ebrahim et al., 1988; Niemi et al., 1988; Nydevik and Hulter-Asberg, 1991, 1992; Viitanen et al., 1988). Åström (Åström, Adolfsson et al., 1992; Åström, Asplund, Åström, 1992) used proxies for a portion of subjects, but did not comment on the usefulness of that technique. Other investigators failed to provide numbers or descriptions of those unable to complete quality-of-life interviews (Angeleri et al., 1993; Lawrence and Christie, 1979; Osberg et al., 1988; Johansson et al., 1992). Thus, the quality of life of persons with stroke who are incapable of completing a questionnaire or interview has never been established.

While it is apparent that quality of life post stroke is diminished, its measurement has been somewhat rudimentary, and a significant proportion of people remain essentially unstudied. Consequently, an accurate description of quality of life of the post-stroke population is lacking.

2.4 Performance-Based Correlates of Quality of Life

The International Classification of Impairments, Disabilities, and Handicaps (ICIDH) is a manual of classification published by the World Health Organization (1980). It groups the consequences of disease into those three broad categories (Badley, 1993). An impairment is a loss or abnormality of psychological, physiological or anatomical structure, whereas the restriction or lack of ability to perform an activity due to impairments is a disability. Handicap occurs when a person is limited or prevented from performing his or her normal role due to impairments and/or disabilities. In the case of a person with stroke an example of an impairment is lack of motor control of the extremities on one side. If that person was unable to walk as a result of the decreased motor control, he or she would be disabled in terms of ambulation. Two people with that same disability might not experience the same handicap. For example, walking would be necessary for a postal worker to do his or her job, but not necessary for a copy editor. The copy editor may have an ambulation disability but not experience an employment handicap.

While the borders between each of the three concepts are somewhat blurred, the model has been useful to rehabilitation researchers and clinicians. Until very recently, the conceptual models of the ICIDH and quality of life have been developing independently. However, in the past two years, numerous authors have called for integration of the models and use of quality-of-life measures in neurological rehabilitation (de Haan, Aaronson et al., 1993; Duncan, 1994; Jette, 1994; Wood-Dauphinee and Kuchler, 1992).

Table 2.4
Descriptive variables for the classification of stroke impairment (Task Force on Stroke Impairment, 1990)

Anatomical Lesion	Clinical Impairment	Comorbidity	Complications
Type	Consciousness	Heart disease	Seizure disorder
Location	Cognitive state	Arthritis	Fractures
Size	Language ability	Orthopedic condition	Pressure sores
	Emotional state	Hearing	Contractures
	Vision	Ophthalmic	Thalamic pain
	Brainstem	Balance	Urinary tract infections
	Limbs (motor&sensory)	Psychiatric/ neurological	Thromboembolus
	Trunk	Diabetes	Reflex sympathetic dyst.
	Standing	Hypertension	Shoulder pain
	Sphincter control	Admission blood pressure	
	Sexual organ impairment	Admission blood sugars	

Table 2.5
Disability variables in stroke outcome research (Task Force on Stroke Disability, 1990)

ADL-Core Performance Tasks	IADL-Complex Performance Tasks	Additional Variables	Leisure and Recreation
Self-care	Meal preparation	Awareness	Hobbies
Locomotion	Use of telephone	Manual Dexterity	Religious Activities
Sphincter Control	Home maintenance		Sexual function
Communications	Money management		Avocations
Cognition/ Behaviour	Use of transportation		Work skills
	Self medication		Use of media(TV,etc)
	Shopping		Quality of life

In 1990, the Task Force on Stroke Impairment and Task Force on Stroke Disability suggested a number of variables for future stroke research (Tables 2.4 and 2.5). The studies reviewed previously have examined some of the relationships between performance-measured impairments and disabilities and quality of life. All studies measured ADL independence, either as an outcome or as an explanatory variable. With the exception of Johansson et al. (1992), Angeleri et al. (1993), and Kappelle et al. (1994), the investigators also examined the ADL scores for an association with quality of life. Other impairments and disabilities suggested by the Task Forces were measured infrequently or never measured. Performance-based measures were not examined for their usefulness as a proxy to quality of life by any of the investigators.

Lawrence and Christie (1979) examined long term stroke survivors in terms of ADL (Rankin Scale (Rankin, 1957)) dichotomized to minimal or moderate disability) and global life satisfaction (optimistic, uncertain, or pessimistic view of the future). An optimistic view of the future was associated with minimal disability, however, over half of the people in the minimal disability group reported being uncertain or pessimistic about their future.

Table 2.6

Performance-measured impairments and disabilities examined in quality of life studies.

First Author	Activities of Daily Living	Ambulation	Motor Impairment
Lawrence, 1979	☑		
Ahlsio, 1984	☑		
Ebrahim, 1986	☑	☑	
Osberg, 1988	☑	☑	
Niemi, 1988	☑	☑	☑
Viitanen, 1988	☑		☑
Nydevik, 1991&'92	☑		
Åström, Adolfsson 1992	☑		
Åström, Asplund, 1992	☑		
Johansson, 1992	☑		
Angeleri, 1993	☑		
Kappelle, 1994	☑		

Using the Katz ADL Index (Katz et al., 1963), Ahlsio et al. (1984) found that global quality of life decreased with increasing dependence in ADL. They noted, however, that there was considerable variation and overlap between the groups. Subjects with diminished quality of life but no ADL disability spontaneously reported the following areas as reasons: diminished walking ability, decreased outdoor leisure and travel, fine motor dysfunction, balance or vertigo, deconditioning, fatigue, worry about a new stroke, depression, decreased concentration, and impaired memory. Interestingly, many of these factors can be assessed with performance-based measures. Most of them have never been examined for an association with quality of life.

Ebrahim et al. (1986) studied 153 patients at one and six months post stroke. Their primary objective was to examine the usefulness of the NHP with this population. Subjects with either improved or diminished ADL capabilities at six months had the worst NHP scores, compared to the subjects who had remained static. This is an unusual finding that does not appear to have been replicated in other studies. Interpretation is made difficult by the lack of a clear description of the ADL measurement tool, as well as the lack of a direct comparison between NHP and ADL scores.

Thirty-nine per cent of four to six year survivors were dependent in ADL in Viitanen and colleagues' (1988) study. While ADL ability correlated well with life satisfaction, almost 30% of those independent in their ADL reported a decrease in life satisfaction.

Using a path analysis, Osberg et al. (1988) attempted to explain life satisfaction at one year following a stroke. ADL independence was measured using the Barthel or Kenny Scales on admission to acute care (stroke onset), and was found have an effect on life satisfaction at one year only after taking social support into account.

Niemi et al. (1988) reported that patients who were independent with ADL had decreased quality of life almost as often as those who are dependent. However, when the severity of the deterioration of quality of life was considered, dependence in ADL was found to be an important factor. Multiple regression analysis by these authors revealed that ADL dependence, along with depression, difficulty in ambulation, and impaired memory quotient explained 73 % of the variance associated with quality of life.

At six to nine months post stroke there was a correlation between high SIP scores (lower quality of life) and ADL dependence in Nydevik and Hulter-Asberg's study (1991). The median SIP score for those independent with ADL was 9.5, whereas for those dependent in ADL it was 44.7.

Also using the Katz Index, Åström, Adolfsson, et al. (1992) found that individuals who were ADL independent at a three month follow-up had significantly higher life satisfaction. Again, a proportion of ADL-independent patients had a decrease in life satisfaction. Of those, many were depressed both in hospital and at the time of follow-up.

Angeleri et al. (1993) measured ADL using the Northwestern University Disability Scale (NUDS) and considered it to be both a part of their composite quality-of-life index, as well as the principal outcome variable in a regression analysis with the other variables: depression, social dysfunction, and family stress. Depression was found to have the greatest influence on ADL. No relationship between our current concept of quality of life and ADL was sought. Similarly, Kappelle and colleagues (1994) assessed both quality of life (parts of SF-36) and ADL (Barthel Index), but did not examine any association between the two.

Although walking ability is part of most ADL indices, including the Barthel and Katz Indices used in many of these studies, its independent effects on quality of life were examined in only two investigations (Niemi et al., 1988; Ebrahim et al., 1986). Ebrahim et al. (1986) found that subjects who couldn't walk had worse NHP scores than those who could, at both one and six months post stroke. As described previously, Niemi et al. (1988) proposed a multivariate model for quality of life which included "difficulties in ambulation." However, no information about this variable is given, and there is no description of how it was assessed. Osberg et al. (1988) didn't measure ambulation, but included wheelchair use as an independent variable. They concluded it impacted indirectly on decreased life satisfaction at twelve months post stroke.

Motor impairments were examined for associations with quality of life in two studies (Niemi et al., 1988; Viitanen et al., 1988). Associations between presence or absence of hemiparesis, coordination disturbances and quality of life were sought by Niemi and colleagues. All of the individuals who had residual hemiparesis and coordination disturbances reported a decreased quality of life, compared to 78% of those with no hemiparesis and 65% of those with normal coordination. While the proportion with diminished quality of life is certainly higher in the more impaired groups, a significant percentage of persons identified as having no impairments had not returned to their pre-stroke levels of satisfaction. Using the Fugl-Meyer Motor Assessment (Fugl-Meyer et al., 1975), Viitanen identified motor impairment in 37% of their cohort. They were categorized as normal or slightly discoordinated, hemiparetic, or hemiplegic. Life satisfaction decreased as the level of impairment increased. As found in other investigations approximately 30% of the subjects classified as having no or mild impairments reported a diminished quality of life.

In terms of identifying and quantifying associations between performance-measured physical disablements and quality of life, a number of problems exist with past studies. Many variables identified by the Task Forces on Stroke Impairment and Disability have never been studied in relation to quality of life, or have been studied by only one or two investigators. For the most part, variables were categorized (ADL-independent versus ADL-dependent; walks versus doesn't walk) and statistical analysis were univariate. Measurement tools were not always known, ideal, or well-described.

With the exception of ADL, impairments and disabilities have been inadequately studied with respect to quality of life. Limb and trunk motor impairments, and locomotion were each evaluated in two studies. Assessments of standing posture and balance, cognition, awareness, and manual dexterity were not found at all. Instrumental activities of daily living (IADL) was ascertained to be associated with quality of life by Åström, Asplund, and Åström (1992), but was notably absent from the other papers.

Most often, statistical analysis were univariate. Multivariate techniques would have strengthened comparisons by allowing for the simultaneous analysis of several variables so their independent contribution could be determined.

The study variables were often dichotomized into categories such as independent in ADL versus dependent, or ambulatory versus non-ambulatory, thereby diminishing the discriminative ability of the instrument. In the cases where stroke patients who were classified as unimpaired reported a diminished quality of life, it is possible that a portion of them have been categorized as normal when they are actually mildly impaired or disabled. Their mild problems may explain some of the diminished quality of life.

It is well established that quality of life is diminished after stroke, and that dependency in ADL contributes to that outcome. The contributions of most other disablements are, however, unknown.

2.5 Summary of Literature

The literature pertaining to stroke is extensive and could not be covered in its entirety; this review intended to provide an overview of stroke in general, and of the quality of life of people who have suffered a stroke. What is clear is that stroke is a major health problem, in Canada and throughout the world. Not only is the mortality associated with stroke very high, but the many of the survivors live with chronic physical, psychological and social problems. As well, the overall health-related quality of life in people who have suffered a stroke is diminished, even when compared to age and gender matched controls. Quality of life does not appear to have been assessed in those stroke survivors who are unable to complete questionnaires or interviews. Furthermore, the associations between many of the residual impairments and disabilities of stroke, most of which can be measured by performance, and quality of life have not been established. Other broad problems with the literature include weak measurements of quality of life, rare use of multivariate statistical analyses, and frequent dichotomization of variables. There are many instances of less than satisfactory quality of life that have yet to be explained.

3.0 OBJECTIVE, HYPOTHESES, & STUDY QUESTIONS

Stroke is a chronic, disabling condition that leaves up to half of its survivors requiring assistance with their basic self care. Many experience a diminished quality of life, however accurate estimates are difficult to obtain because of measurement difficulties in previous studies. The contributions of the specific factors to the health-related quality of life in persons with stroke remain, for the most part, undiscovered. Moreover, 10% to 27% of persons with stroke have been excluded from quality of life studies as they are unable to complete the questionnaires or interviews.

This study was proposed to further clarify the attributes of quality of life in persons with stroke, and to determine which observable impairments and disabilities might be used to estimate quality of life in non-communicative individuals. The specific objective is: to determine the associations between performance-based measures of physical function and health-related quality of life as reported by persons one year post-stroke living in the community. Specific questions and hypothesized answers are as follows:

1. Can a measure which relies on the actual performance of tasks be used to explain some or all of the components of health-related quality of life? *Hypothesis: A combination of physical performance measures will be able to explain a significant proportion of the variance in the physical component of quality of life. The mental health component will be explained less accurately.*

2. Are performance-based disability measures more strongly correlated with health-related quality of life than performance-based measures of impairments? *Hypothesis: Disability measures will explain more variance in health-related quality of life than will impairment measures.*

In order to answer these questions, a study was proposed and initiated in the fall of 1994. The following chapters describe the methods, results, and conclusions of that project.

4.0 METHODOLOGY

4.1 Overview & Study Design

A cross-sectional study of community dwelling individuals 10 to 16 months post stroke was conducted in order to examine the relationships between performance-based measures of impairment and disability and health-related quality of life. Subjects were recruited from patients who had been hospitalized with a stroke at the Montreal General Hospital between September, 1993 and August, 1994. Those who were eligible and who agreed to participate responded to questionnaires administered by telephone interview measuring quality of life, activities of daily living, instrumental activities of daily living and cognitive status. In addition, their gait, manual dexterity, neurological motor recovery, and perception were evaluated at a home visit by a physiotherapist (S.M.). Forty-five subjects participated in the study. Descriptive statistics were compiled to characterize the population. Multiple linear regression analysis was performed to explain the associations between the performance-based measures and the components of health-related quality of life.

4.2 Study Population

One year survivors of their first stroke in the city of Montreal, Quebec were targeted for this investigation. "Stroke" was defined by the World Health Organization (1980) as "rapidly developing clinical signs of focal (or sometimes global) disturbances of cerebral function lasting more than 24 hours or leading to death with no apparent cause other than that of vascular origin." Dr. Robert Côté of the Montreal General Hospital's Neurology Department agreed to permit recruitment of patients admitted for stroke in the year prior to this study. Most subjects were recruited from a stroke registry set up by Dr. Côté to follow persons after a stroke for episodes of seizure. Subjects who came to the Emergency Department with a suspected stroke were registered by a research assistant, and asked to participate in a prospective study to determine the incidence of seizure post-stroke. That registry was used to facilitate recruitment. In addition, to attempt to reach every eligible candidate, a report of all stroke discharges from September 1, 1993 and August 31, 1994 was generated by the Medical Records Department at the Montreal General Hospital. Thus, some individuals who were not included in the stroke registry, such as those who had a stroke while in hospital for another medical reason, or those transferred from a community hospital, were also contacted as potential participants. The report compiled medical chart numbers for discharged patients having the following ICD9[4] codes: 431, intra-cerebral hemorrhage; 432, other intra-cranial hemorrhage; 433, occlusion of precerebral arteries; 434, occlusion of cerebral arteries; 436, acute, ill-defined cerebrovascular disease; and 437, other and ill-defined cerebrovascular disease.

Table 4.1
Inclusion and exclusion criteria

Eligible	Ineligible
>=50 years old	Stroke due to metastatic disease
French or English Speaking	Subarachnoid hemorrhage
10 to 16 months post stroke	Subdural hematoma
Living at home 1 month or more	Incapable of completing phone interview
Living in the Montreal area	

To be eligible, the individual had to be 50 years old or more, speak French or English, be between 10 and 16 months post stroke onset, be discharged home for at least one month, and be living in the Montreal area. It was hypothesized that this group would have a relatively stable quality of life, having had one year to adjust to their illness, and at least one month to re-adjust to their home environment. As well, most stroke recovery has occurred by six months (Mayo, 1993). Excluded from the study were persons who had

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[4] International Classification of Diseases.

sustained a stroke secondary to metastatic disease, subarachnoid hemorrhage, or subdural hematoma, as well as those individuals incapable of completing a telephone quality-of-life interview. The latter exclusion was necessary in light of the study design. Young people with stroke, as well as people with stroke due to metastatic disease were excluded because their quality of life and the factors influencing it are probably different from those of the target population. Subarachnoid hemorrhage and subdural hematomas were excluded because of their causes and presentations are different from those of thromboembolic stroke or cerebral hemorrhage.

4.3 Procedures

Names of patients who had sustained a stroke were obtained from the stroke registry and the charts listed in the Medical Record's report. Eligible candidates were identified by chart review and were sent a letter explaining the study. The principal investigator (Sara McEwen) contacted the potential participant by telephone about one week later. If they were hospitalized at that time, living in a nursing home, or found to be incapable of completing a telephone interview, they were excluded. All others were asked to participate. If agreeable, appointments for the home visit and telephone interview with the patient were arranged.

The quality-of-life questionnaire (SF-36) was administered over the telephone by independent, trained interviewers[5]. At the same time, questionnaires to assess cognitive status, activities of daily living (ADL), and instrumental activities of daily living (IADL) were administered. The home assessor was not provided with the results of these evaluations prior to her evaluation. In most cases, the telephone interview was scheduled to occur within one week prior to the home visit. Signed, informed consent was obtained at the home.

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[5] Penny Baylis, Claudette Corrigan, Lise Magnan, Lina Petrulli, or Jane Sutherland.

Telephone interview was the method chosen for the evaluation of quality of life, other non-performance indices, and the ADL and instrumental ADL measures. This was to shorten the duration of the home visit, and so that the home assessor could be blind to the subjects' self-reported quality of life. Results from telephone interviews correlate highly with face-to-face interviews (Korner-Bitensky et al., 1994, 1995)

Subjects were assessed at home by a physiotherapist (S.M.). For reasons of safety and efficiency, a second physiotherapist (Carron Gordon) was present during the home visits. Gait, manual dexterity, perception, and neurological motor recovery were assessed during the performance of tasks. The order of the tests did not follow a rigidly fixed pattern, however, sitting and standing tasks were alternated to avoid fatigue.

4.4 Instrumentation

The outcome variable of this study was self-perceived quality of life. It was evaluated by the Medical Outcomes Study 36-Item Short-Form Health Survey (Ware and Sherbourne, 1992). This generic health measure was developed to assess health-related quality-of-life outcomes that are closely affected by disease and treatment. In total, eight health concepts are assessed by the SF-36: 1) limitations in physical activities because of health problems; 2) limitations in social activities because of health problems; 3) limitations in usual role activities because of physical health problems; 4) bodily pain; 5) general mental health (psychological distress and well-being); 6) limitations in usual role activities because of emotional problems; 7) vitality (energy and fatigue); 8) general health perceptions. Each of the eight sections is examined separately and given a score between 0 and 100. As well, the scale's authors used principal components analysis to reduce the SF-36 to two summary scores representing physical and mental health (Ware, 1994). These summaries are based on normal values from the United States population, and are transformed to have a mean score of 50 and a standard deviation of 10.

The SF-36 was selected to measure quality of life in this study because of its strong psychometric properties and because it is easy and practical to administer. As well, it has undergone careful translation into several languages, including Quebec French. (Aaronson et al., 1992). The SF-36 has been rigorously tested and has demonstrated good reliability, validity, and responsiveness. Internal reliability, assessed with Chronbach's alpha, was greater than 0.85 and the reliability coefficient greater than 0.75 for all dimensions in a study by Brazier and colleagues (1992). The instrument has a relative precision of 0.93 (McHorney et al., 1992). The SF-36 has demonstrated responsiveness (Katz et al., 1992), content validity (Ware and Sherbourne, 1992), and construct validity (McHorney et al, 1992; 1993). Evidence of this scale's validity in the elderly population has been published (Lyons et al., 1994) As well, low levels of ill health may be detected by this instrument that are classified as normal by the Nottingham Health Profile (Brazier et al., 1992).

Short-form multi-item scales, such as the SF-36, offer a good compromise between practical considerations (responder burden of long-form scales) and psychometric standards (decreased reliability of single-item scales) (McHorney et al., 1992). The SF-36 is a practical choice, as it takes approximately ten minutes to administer. It has been validated for use on the telephone and a standardized protocol for this method of administration has been developed (Ware, 1993). Possible ceiling and floor effects are a disadvantage of using short-form scales (Ware and Sherbourne, 1992), however the use of the norm-based Physical and Mental Health Summary Scores of the SF-36 eliminates that problem (Ware, 1994).

Detailed assessments of physical impairments and disabilities were made with standardized, reliable and valid performance-based instruments. Impairment was measured by examining the neurological recovery of the limbs and trunk using the Chedoke-McMaster Stroke Assessment Impairment Inventory (Gowland et al., 1993). The disabilities measured were: ADL, using the Barthel Index (Mahoney and Barthel, 1965), instrumental ADL (IADL) using the Older Americans Resources and Services (OARS) IADL scale (Duke University Center for the Study of Aging and Human Development, 1978); mobility, using the Timed Up and Go, (Podsiadlo and Richardson, 1991); perception , using Albert's Test (Albert, 1973); and gross manual dexterity, using the Box and Block Test (Cromwell, 1965). All of the selected tests required minimal time and equipment to administer.

The Chedoke-McMaster Stroke Assessment (Gowland et al., 1993) contains an Impairment Inventory and a Disability Inventory. Only the Impairment Inventory was used, as the Timed Up and Go was selected as a measure of mobility-related disability. The Impairment Inventory rates seven stages of motor recovery, as described by Brunnstrom (1970), for each of the hand, arm, leg, foot, and postural control. The sixth dimension of the scale, shoulder pain, is also scored on a seven point scale, but on the basis of severity rather than motor recovery. The scores for each dimensions are summed to provide a summary score out of 42. Gowland (1993) reported intra- and interrater reliabilities of the impairment scales to range between 0.85 and 0.96 (Intraclass Correlation Coefficient, ICC). As well, the Impairment Inventory correlated (r=0.95) with a similar test, the Fugl-Meyer Measure (Fugl-Meyer et al., 1975), thus demonstrating criterion validity. The Impairment Inventory takes approximately 15 minutes to administer and requires no special equipment. Standardized administration procedures are available (Gowland et al., 1995).

Chosen as a measure of ADL was the widely known Barthel Index (Mahoney and Barthel, 1965). The Barthel Index has been extensively used with the elderly, and stoke patients in particular (Wellwood et al., 1995). It consists of ten items of mobility and self care, and can be evaluated by performance and observation. This scale correlates with other ADL indices (Wylie, 1967) and exhibits good reliability and internal consistency (Collin et al., 1988). A potential problem with the Barthel Index is a ceiling effect in community-dwelling elderly persons (Wellwood et al., 1995). In order to provide higher level ADL information, the IADL section of the OARS Multidimensional Functional Assessment was added. This section of the OARS has demonstrated good interrater reliability (ICC=.865), and the entire activities of daily living scale (ADL and IADL together) have good content and criterion validity (Fillenbaum and Smyer, 1981). In a 1985 article by George and Fillenbaum, it is indicated that the ADL scale may be broken down into its two components and each can stand alone. The OARS ADL is very similar to the Barthel Index, thus only the IADL section will be used.

In the Timed Up and Go, the subject is timed as they rise from a chair, walk three metres, turn, walk back, and sit down. This test is reliable, both between and within raters, as well as being correlated with the Berg Balance Scale (Berg et al., 1989) (r= -0.81), the Barthel Index (r= -0.78), and gait speed (r= 0.61) (Podsiadlo and Richardson, 1991). Less than five minutes are required to complete this test. A chair, a stopwatch, and three metres of space are required.

Albert's Test of perceptual neglect (Albert, 1973) requires the patient to cross out all of 40 lines distributed evenly on a piece of paper. The percentage of lines left uncrossed gives the test score, and if more than 70 % of the uncrossed lines are on the same side as the patient's motor deficit, lateralized neglect is indicated. Fullerton, McSherry, and Stout (1986) found that the results of this test were closely related to a full perception test battery, as well as being predictive of both mortality and functional activity at six months. Albert's Test can be completed in a few minutes.

The Box and Block Test (Cromwell, 1965) measures gross unilateral manual dexterity. The person being tested is required to move, one by one, the maximum number of blocks from one compartment of a box to another of equal size within one minute. Cromwell (1965) indicated that the test-retest reliability is greater than 0.9 for both the dominant and non-dominant hand, and that the test correlated highly (r=0.91) with another similar test of dexterity. Desrosiers and colleagues (1994) recently verified the test-retest reliability and construct validity of this instrument in the elderly population with upper limb impairment. Of the 33 people in their study population, 13 subjects had hemiparesis or hemiplegia following a stroke. The ICC's ranged from 0.89 to 0.97, and significant correlations were demonstrated between the Box and Block Test, an upper limb performance measure, and a measure of functional independence. The Box and Block Test, as with the majority of tests selected, requires only a few minutes to administer.

Comorbidity, cognition, depression, and pre-stroke health-related quality of life were identified as important potential confounders in this study. Also considered and assessed as confounders were age, gender, and type and side of stroke.

Comorbidity was evaluated using the Charlson Comorbidity Index (Charlson, 1987). Although it was designed for use with prospective mortality research, it was recently used in a cross-sectional quality of life study (Mangione et al., 1993). This index sums comorbid conditions with high-fatality diseases being most strongly weighted. The information necessary to compile the index was obtained from the stroke registry, the patient's chart, and patient interview. Important comorbid conditions not included in the index, such as hypertension and angina, were also noted and summed.

Cognitive status was ascertained using Pfeiffer's (1975) Short Portable Mental Status Questionnaire (SPMSQ). Ten questions are asked; the respondent is given one point for a correct answer, and zero for a wrong answer. Scores of less than six indicate cognitive impairment. It has shown good agreement with a clinical classification of organic brain syndrome in community residents (Pfeiffer, 1975). The SPMSQ can be administered over the telephone in a few minutes.

The Geriatric Depression Scale (Yesavage and Brink, 1983) was administered during the home visit in order to screen for depression. It consists of 30 questions answered as "yes" or "no," is scored out of 30, and is self-rated. Scores of nine or greater have a 90% sensitivity and 80% specificity to detect depression in the elderly. The Geriatric Depression Scale has been validated for use with community dwelling, well elderly people (Steuer et al., 1984).

Pre-stroke quality of life is difficult to ascertain. Question two of the SF-36 asks the "compared to one year ago, how would you rate your health in general now? - much better now than one year ago, somewhat better now than one year ago, about the same as one year ago, somewhat worse than one year ago, much worse than one year ago." The data from that section was analyzed separately to evaluate the confounding effect of pre-stroke status. Unfortunately, there may be a certain "rose-coloured glasses" bias associated with recalling pre-stroke status.

Table 4.2
Variables and measurement instruments

Variable	Type	Instrument
Quality of Life	Outcome	SF-36 (T)
Motor Recovery of Limbs	Explanatory	Chedoke-McMaster SAS (H)
Gait	Explanatory	Timed Up and Go (H)
Manual Dexterity	Explanatory	Box and Block Test (H)
ADL	Explanatory	Barthel Index (T)
IADL	Explanatory	OARS IADL (T)
Perception	Explanatory	Albert's Test (H)
Comorbidity	Confounding	Charlson Comorbidity Index (C)
Cognitive Status	Confounding	SPMSQ (T)
Depression	Confounding	Geriatric Depression Scale (H)
Pre-stroke Quality of Life	Confounding	SF-36 (T)

(H=administered at home, T=administered by telephone interview, C=information from chart review)
Copies of all instruments are found in Appendix B.

4.5 Data Analysis

The data analyses were performed in four steps: similarity between the participants and non-participants was verified; the study sample was described, similarity between those who completed French questionnaires and those who completed English ones was verified, and, finally, associations between the performance-based measures and health-related quality of life were determined.

In order to verify similarity between participants and non-participants, proportions were calculated for the variables gender, language, type of stroke (ischemic, hemorrhagic, or unclear), and side of stroke (right, left, or bilateral) for each of two groups: study participants, and non-participants. As well, the mean age was determined for each group. The two groups were then compared to ensure they were not different. For the proportions, chi-squared tests were performed. To test for a difference between the mean ages, a t-test was used.

Means, medians, standard deviations, as well as minimum and maximum values were calculated for all outcome and explanatory variables in order to provide a thorough description of the sample. As well, descriptive statistics were compiled for the confounding variables.

The similarity between those patients who responded to French questionnaires and those who responded to English questionnaires was examined by comparing the mean values of each, using a t-test. The null hypothesis tested was that a difference existed between the people who responded to the different language versions of the questionnaires. Non-significant differences would indicate that the two groups were similar, and that they could be pooled as one group.

To determine associations between the outcome variables, dimension-specific quality of life and SF-36 Mental and Physical Summary Scores, and the explanatory variables, both univariate and multivariate analyses were employed. To determine all possible univariate associations, Pearson Correlation Coefficients were determined for each pair of variables. As well, simple linear regression was performed, using each performance-based variable in turn as the explanatory variable for both the Physical Health Summary Score and the Mental Health Summary Score of the SF-36 as outcome.

Multivariate analysis techniques are used when one wishes to examine the effects of two or more "X" (explanatory variables) simultaneously on a single "Y" (outcome) variable. In particular, multiple linear regression is the technique of choice when both the explanatory and outcome variables can be analyzed as continuous data. The regression model takes the following form:

$$Yi = ßi_0 + ßi_1Xi_1 + ßi_2Xi_2 + \ldots + ßi_pXi_p + \text{error}$$

where i is a given subject, $X1$, $X2$, ... Xp are the explanatory variables, $ß_0$ is the y-intercept, and $ß_{1,2,..p}$ is the rate of change of Y with respect to X. Details about the model development and the assumptions of multiple linear regression are given in the following chapters.

In the case of this study, multiple linear regression was indicated to identify the interrelationships amongst the performance-based variables, as well as to adjust for the effects of important confounding variables such as age.

4.6 Ethical Considerations

Ethical guidelines for research involving human subjects were established by the Medical Research Council of Canada in 1987. The fundamental ethical principle in research is respect for human life. The principles of informed consent, the balancing of benefits and risks, and confidentiality all stem from that basic standard.

An individual's consent to involvement in a study should be informed and voluntary, and in the province of Quebec, it must be written. Furthermore, obtainment of consent at the beginning of a study is a minimum requirement, and education should continue throughout the person's time of participation. Amongst the information provided, there must be a clear declaration of all real and potential risks involved.

A person participating in any study has the right to complete confidentiality. Confidentiality implies not only privacy of all personal information, but also that the individual should not be approached by a stranger who knows his or her medical history.

These ethical principles guided the design and implementation of this study. An explanation of the study and of the burden on the subject was provided to all participants, and their informed, written consent was obtained. Furthermore, every effort was made to adequately answer any questions they had throughout the evaluations. The confidentiality of all personal information was carefully protected, and encoded as soon as feasible. Potential participants were not initially contacted by a stranger, but instead by a doctor from the hospital where they had been admitted at the onset of stroke. They were first sent a letter from the doctor explaining the study, which also forewarned them that they would be receiving a telephone call. (Appendix A contain copies of the contact letters and consent forms)

The activities performed by the participants were everyday tasks, thus the risk involved was negligible. Furthermore, as an extra safety measure, two people (S.M. and C.G.) were present at the home assessment sessions. The potential benefits of new knowledge about the quality of life of stroke patients certainly outweighed the minimal risks involved.

This study was approved by ethics committees at both the Montreal General Hospital and at McGill University's School of Physical and Occupational Therapy.

5.0 RESULTS

5.1 Introduction

In this chapter, the main results from the study are presented. The data analyses were performed with the goals of describing the study sample, verifying similarity between the participants and non-participants, as well as between those who completed French questionnaires and those who completed English ones, and, finally, answering the specific questions put forth in Chapter Three. Section 5.2 describes the sampling population and lists reasons for non-participation. Important characteristics of the participants are given, and they are compared, where possible, to those of the non-participants. Potential language bias is examined in Section 5.3, by comparing the scores from the French measures to those from the English measures. Descriptive statistics for the study outcome, health-related quality of life as measured by the SF-36, are summarized in Section 5.4. The descriptive statistics for the performance-based measures are given in Section 5.5. The principal objective of this study was to determine the associations between performance-based measures and health-related quality of life. Univariate and multivariate associations amongst the variables are presented in Section 5.6, in order to answer the questions associated with that objective. The final section of the chapter recapitulates the results.

5.2 Description of the Study Population

A chart review of persons treated for stroke at the Montreal General Hospital between September 1, 1993 and August 31, 1994 revealed that eighty-eight people met the eligibility criteria. Of those, 45 (51%) agreed to participate. The reasons for not participating are given in Table 5.1. Eighteen individuals were not traced, and 10 were deceased. The refusal rate was low; only six people declined participation.

TABLE 5.1

Reasons for non-participation

Reason	Frequency	Per Cent
Unable to trace	18	41.8
Deceased	10	23.2
Unable to do phone interview	6	13.9
Refused	6	13.9
Residing in long-term care facility	3	7.0
Total	43	*100.0

* May not total exactly 100 due to rounding error.

Although 45 people agreed to participate in this study, complete data are available for only 43 subjects. One woman completed the phone interview, but became ill before the home assessment was done. A man finished the home assessment but did not do the telephone interview. A 91 year-old woman answered the questionnaires at a face-to-face interview because she was too deaf to be interviewed over the telephone, but she was keen to participate. For this case, the home assessor remained blind to the interview responses.

Slightly more than half of the participants were male. Together, the men and women had a mean age of 70.1 years, were an average of 14 months post stroke and were mostly English-speaking. They all demonstrated adequate cognitive abilities, scoring six or more (out of a maximum of 10) on the Short Portable Mental Status Questionnaire, and all but two scored seven or higher. Participants had an average of 1.9 comorbid conditions, but half of the sample had none or only one. Eleven participants, about one-quarter of the sample, scored nine or higher on the Geriatric Depression Scale, indicating possible depression. The profile of the sample in terms of the type and side of stroke was as expected. Three-quarters of them had an ischemic cerebrovascular accident (CVA), and the location of stroke was approximately evenly distributed between right and left sides. The principal characteristics of the sample are given in Table 5.2, along with the values for the non-participants. There were no statistically significant differences between the two groups for age, gender, language, laterality, or type of stroke.

TABLE 5.2

Comparison of the characteristics of study participants and non-participants

	Participants (n=45) % (#)	Non-Participants (n=43) % (#)	Chi-Square *p-value*
Men	57.8 (26)	44.2 (19)	1.63
Women	42.2 (19)	55.8 (24)	*0.20*
French	28.9 (13)	32.6 (14)	1.14
English	71.1 (32)	67.5 (29)	*0.30*
Right CVA	48.9 (22)	41.9 (18)	0.89
Left CVA	46.7 (21)	55.8 (24)	*0.64*
Bilateral CVA	4.4 (2)	2.8 (1)	
Ischemic	73.3 (33)	86.0 (37)	2.31
Hemorrhagic	20.0 (9)	9.3 (4)	*0.32*
Not specified	6.7 (3)	4.7 (2)	
Mean age	70.1	72.6	*1.14 *0.26*

CVA=cerebrovascular accident *t-test, comparing mean ages

5.3 Comparison of French and English Versions of Questionnaires

In the city of Montreal, both the English and French languages are used. Therefore, it was necessary to use two different versions of many of the measures. The mean scores for those who completed interviews in French were compared to the mean scores of those who used English, and the results are presented in Table 5.3. While the French scores for several of the SF-36 subscales were lower, no statistically significant differences were found between those two groups. For the remainder of the analyses, the French and English versions of all questionnaires and indices were pooled with confidence that they were measuring similar constructs.

TABLE 5.3

Comparison of mean scores of English versus French measures

Measure	English Score (n=32) Mean (SD)	French Score (n=13) Mean (SD)	T-test T (p-value)
SF-36 Subscales & Summaries			
General Health	65.9 (18.8)	66.7 (22.0)	0.12 (0.90)
Physical Role Limitations	49.2 (37.9)	50.0 (44.5)	0.06 (0.95)
Emotional Role Limitations	80.6 (31.9)	71.8 (44.8)	-0.74 (0.46)
Physical Functioning	63.2 (29.6)	53.8 (31.7)	-0.94 (0.35)
Social Functioning	81.4 (27.5)	76.9 (32.6)	-0.47 (0.64)
Bodily Pain	75.8 (27.8)	66.3 (32.6)	-0.95 (0.33)
Vitality	55.6 (22.5)	48.8 (25.2)	-0.88 (0.38)
Mental Health	77.2 (21.7)	70.8 (22.4)	-0.88 (0.38)
Physical Summary Score	42.1 (10.2)	40.1 (13.3)	-0.55 (0.59)
Mental Summary Score	53.5 (11.2)	50.1 (13.1)	-0.87 (0.39)
Performance Measures			
Barthel Index	94.9 (12.2)	95.0 (7.1)	0.03 (0.98)
OARS ADL/IADL	25.3 (4.9)	25.3 (3.8)	0.03 (0.98)
Clinical Confounding Variable			
Geriatric Depression Scale	7.1 (5.8)	6.5 (4.2)	-0.35 (0.73)

5.4 Health-Related Quality of Life: Descriptive Statistics for the SF-36

In this section, means, medians, standard deviations, as well as minimum and maximum values are given for all eight subscales and the two summary scores of the Medical Outcomes Study 36-Item Short Form Questionnaire. As well, gender-specific and age-specific means are listed for the Physical Health Summary Score and the Mental Health Summary Score. Tables 5.4 and 5.5 summarize these values.

Table 5.4

Descriptive statistics for the SF-36 eight subscales and two summary scales (n=44)

Variable	Mean	SD	Lowest	Median	Highest
Scores for the 8 subscales					
(0-100 for all scales)					
General Health	65.4	19.9	25.0	64.5	100.0
Physical Role Limitations	49.4	39.4	0.0	50.0	100.0
Emotional Role Limitations	78.0	35.9	0.0	100.0	100.0
Physical Functioning	60.5	30.2	0.0	67.5	100.0
Social Functioning	80.1	28.8	0.0	93.8	100.0
Bodily Pain	73.0	29.3	0.0	73.0	100.0
Vitality	53.6	23.2	0.0	55.0	100.0
Mental Health	75.3	21.8	16.0	84.0	100.0
Scores for the Mental and Physical Summary Scores					
Mental Health Summary Score (MCS)	52.2	11.8	18.4	55.2	67.6
Physical Health Summary Score (PCS)	41.1	11.2	14.2	42.0	60.1

SD=Standard Deviation

Table 5.5

Descriptive statistics for Physical and Mental Health Summary Scores by age and gender (n=44)

Variable	Mean	SD	Lowest	Median	Highest
Men (n=26)					
Mental Health Summary Score	54.0	8.8	23.3	56.7	66.6
Physical Health Summary Score	41.7	9.6	32.5	43.5	57.6
Women (n=18)					
Mental Health Summary Score	50.4	14.9	18.4	54.9	67.6
Physical Health Summary Score	41.2	13.2	14.6	37.1	60.1
Ages 50-64 (n=13)					
Mental Health Summary Score	52.8	8.1	37.5	55.0	64.2
Physical Health Summary Score	45.8	11.5	25.0	49.4	60.1
Ages 65-74 (n=15)					
Mental Health Summary Score	54.2	8.4	32.5	54.7	66.6
Physical Health Summary Score	39.5	9.5	23.3	35.7	55.4
Ages 75+ (n=17)					
Mental Health Summary Score	49.7	16.5	18.4	56.7	67.6
Physical Health Summary Score	38.9	12.1	14.2	41.8	54.6

SD=Standard Deviation

Table 5.6

Descriptive statistics for performance measures (n=44)

Variable	Mean	SD	Lowest	Median	Highest
OARS IADL Index (0-14)	11.6	3.2	2.0	13.0	14.0
Barthel ADL Index (0-100)	94.8	10.7	45.0	100.0	100.0
Timed Up and Go (timed, target <10 seconds)	11.1	9.2	60.0	8.9	4.8
Bock & Block Test (Hemiplegic Hand) (0-150)	49.0	18.4	0.0	53.5	74.0
Box & Block Test (Normal Hand) (0-150)	57.7	13.6	16.0	60.0	82.0
Albert's Test of Perception (40-0)	1.7	5.5	35.0	0.0	0.0
Chedoke-McMaster Impairment Inventory (7-42)	37.9	4.8	23.0	39.5	42.0
Stage of Hand (1-7)	6.3	1.2	2.0	7.0	7.0
Stage of Arm (1-7)	6.3	1.2	2.0	7.0	7.0
Stage of Leg (1-7)	6.3	0.8	4.0	6.0	7.0
Stage of Foot (1-7)	6.2	1.0	3.0	6.0	7.0
Shoulder Pain (1-7)	6.4	1.0	4.0	7.0	7.0
Stage of Postural Control (1-7)	6.4	0.9	3.0	7.0	7.0

SD=Standard Deviation

Each of the eight health dimensions of the SF-36 is scored out of 100, with higher scores indicating better health-related quality of life. Mean values for the 44 stroke patients interviewed in this study range from 49.4 for Physical Role Limitations to 80.1 for Social Functioning. The Summary Scores are transformed based on United States population normative values to have a mean of 50 and a standard deviation of 10. This sample has a mean Mental Health Summary Score of 52.2, and a mean Physical Health Summary Score of 41.1. The methods for transforming the scores are described in Appendix C.

5.5 Performance-Based Measures: Descriptive Statistics

The performance measures assessed in this study are summarized in Table 5.6 The mean and median, standard deviation, and lowest and highest observed score are provided for each. The possible scoring range is listed below each variable, with the number on the right being the most desirable score. Higher numbers indicate better scores for all variables with the exception of Albert's Test of Perceptual Neglect, for which zero is the target; and for the Timed Up and Go, for which lower times indicate better mobility.

This community-dwelling sample had mean scores towards the more desirable end for all measures, indicating that they were a high functioning group. For example, the mean OARS IADL was 11.6 out of a possible 14, and the mean Barthel was 94.8 out of a possible 100. Nonetheless, the worst scores demonstrate that there were individuals in the sample who were functioning at a relatively low level.

5.6 Associations Between Performance-Based Measures and Health-Related Quality of Life

The principal objective of this study was to determine which performance-based measures correlated highly with health-related quality of life reported by persons 12 months post-stroke living in the community. In this section, analyses directed at answering the specific study questions associated with that objective are presented. Univariate and multivariate associations were established between the performance-measured explanatory variables and all confounding variables with the outcome, health-related quality of life.

The analyses of associations included a number of steps. Initially, univariate associations were determined by calculating Pearson correlation coefficients for all pairs of variables and by performing simple linear regression for all performance and confounding variables on both the SF-36 Physical and Mental Health Summary Scores. The assumptions for regression analyses were verified. Then, all performance-based variables were examined for interactions with age and sex. Finally, multivariate models were developed using the statistical software SAS®[6] Version 6, General Linear Modeling (GLM) procedure and a backwards elimination technique.

The Pearson correlation analysis revealed many significant associations, but very few of them were strong. Correlations between the Physical Health Summary Score and the physical performance measures ranged in value from 0.49, with the Chedoke-McMaster Stroke Assessment Scale, Impairment Inventory, to 0.04 with Albert's Test of Perceptual Neglect. The Mental Health Summary Score, on the other hand, correlated with Albert's Test at -0.44, but was uncorrelated with the Chedoke-McMaster Stroke Assessment Scale Impairment Inventory, scoring only -0.03. Interestingly, the Mental and Physical Summary Scores were similarly correlated with the OARS IADL scale, with Pearson coefficients of 0.43 and 0.49 respectively. Graph 5.1 compares the Pearson correlation coefficients of the Mental Health Summary Score and the Physical Health Summary Score for each of the performance-based variables. The full correlation matrix is presented in Appendix D.

Parameter estimates for each independent variable are given for simple regression

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[6] SAS Institute Incorporated, SAS Campus Drive, Cary, North Carolina, U.S.A. 27513

on both the Physical Health Summary Score and the Mental Health Summary Score in Table 5.7. This value, known as ß, is the amount of change in the dependent variable onecan expect to see for every one unit change in the independent variable. In this case, the SF-36 Summary Scores are the dependent variables, and the performance measures and confounders are independent variables. In order to proceed with simple linear regression, it is necessary that certain assumptions are met. The assumptions, normality, linearity, homoscedasticity, existence, and independence, are discussed in detail in Chapter Six. In order to satisfy the assumption of normality, it was necessary to transform the Mental Health Summary Score to its squared form. Furthermore, the Barthel Index and Albert's Test appeared to be non-linear when plotted against the Mental and Physical Health Summary Scores. Thus, those variables were classified into two groups, based on their median values, and analyzed as categorical variables.

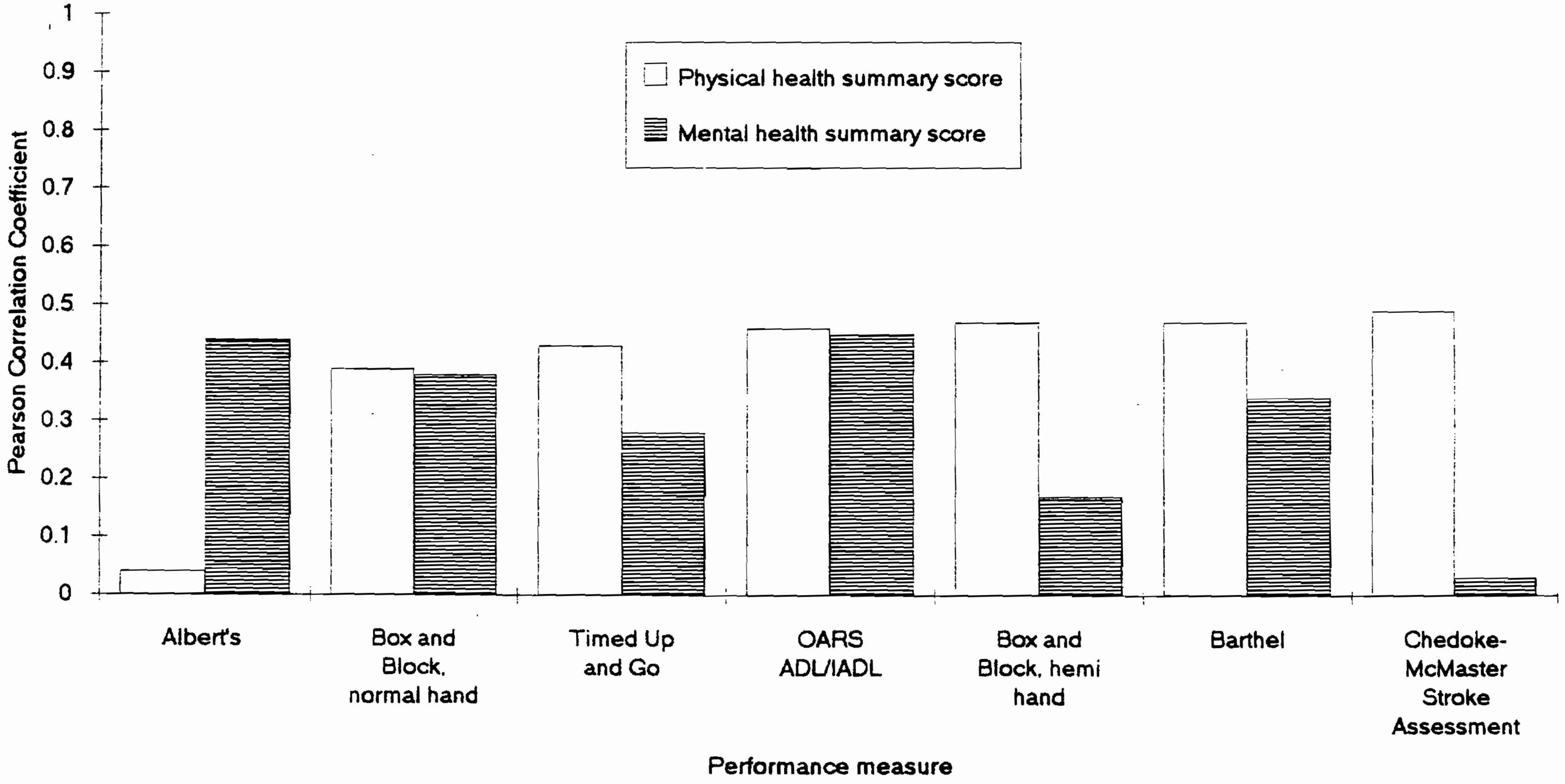
All performance measures, with the exception of Albert's Test, were significant predictors of physical health. Mental health was predicted by the OARS IADL Index, the Barthel Index, the normal hand score for the Box and Block Test, and Albert's Test of Perceptual Neglect. Although several of the univariate models were significant, the amount of variation explained by them was low. The r-squared values for the significant performance-measures ranged from 0.11 to 0.24.

In preparation for the multiple regression modeling, significant interactions with age or gender for any of the performance-based variables with either mental health or physical health were sought. The interaction terms that were significant independent predictors for the Physical Health Summary Score were the Box and Block Test for the hemiplegic hand with gender , as well as age and gender together. For the Mental Health Summary Score, significant interactions were seen with the OARS IADL scale and gender, as well as with the Box and Block Test for the normal hand and gender.

Because of the interactions of some variables, it was hypothesized that gender-

Graph 5.1

Pearson correlation coefficients of performance measures with SF-36 Summary Scores



specific multivariate models would be able to predict[7] the outcomes more accurately. Thus, separate models for men and women were developed for both the squared Mental Health Summary Score and the Physical Health Summary Score. In addition, simple linear regression was conducted to determine the univariate gender-specific parameter estimates for the performance measures on the SF-36 Summary Scores. Those values are found in Table 5.8. The significant r-squared values for the gender-specific univariate estimates were higher than those determined for the full sample, ranging from 0.21 to 0.50. Notably, in men, 31%, and 36% of the variation in the Physical Health Summary Score was explained by the Box and Block Test for the normal hand, and the Box and Block Test for the hemiplegic hand.. In women, 41% of the variation in the Mental Health Summary Score was explained by the Box and Block Test for the normal hand, and 50% was explained by the OARS IADL Index.

Using the statistical software SAS®[8] Version 6, the General Linear Modeling procedure was performed with the goal of determining the best combination of performance measures to explain the variation in the SF-36 Summary Scores. The assumptions for multiple linear regression are similar to those for simple linear regression, thus the squared Mental Health Summary Score was maintained as one of the two main outcomes, and the Barthel Index and Albert's Test were analyzed as categorical variables. The combination of variables that explained the highest proportion of variation in the outcomes, as determined by the r-squared value, was considered to be the best model. A backwards elimination technique was employed; that is to say, the model started with all performance and confounding variables which were then eliminated one by one until the model contained only independent predictors. The correlation matrix of all study variables (Appendix D) indicates that some of the performance variables are highly correlated with

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[7] For the purposes of reporting these results, "prediction" refers to the ability of the model to determine a PCS or MCS score that is close to the true, or observed value, for a specific subject. It does not refer to the models ability to "predict" any future events.

[8] SAS Institute Incorporated, SAS Campus Drive, Cary, North Carolina, U.S.A. 27513

one another. The Timed Up and Go is correlated with the OARS IADL Scale at r=-0.88, and with the Barthel Index at r=-0.92. The Chedoke McMaster Stroke Assessment Scale, Impairment Inventory is correlated with the Box and BlockTest for the hemiplegic hand at r=0.82. Thus, to avoid problems of collinearity in the models, only one of a highly correlated[9] pair was entered into the model at a time.

After the final models were developed, the non-patient-reported[10] confounding variables were re-introduced one at a time, in order to determine whether or not they significantly altered the parameter estimates. Social support, number of comorbid conditions, and age, were all examined for their effect on the Physical and Mental Health Summary Score models. The parameter estimates were then adjusted for any variables that changed them by more than 10% in either direction. All three models were adjusted for age, but none of the other potential confounders were found to change the parameter estimates by more than 10%. However, the addition of age to the model for men's physical health caused the Barthel Index to be eliminated from the model -- it was no longer a strong independent predictor.

The final models, along with the parameter estimates for each variable, are given in Tables 5.9. The Mental Health Summary Score model for women included the OARS IADL Index and the Chedoke-McMaster Stroke Assessment Scale, Impairment Inventory, and explained 66% of the variations in that score. The Physical Health Summary Score specific to men achieved an r^2 of 0.39, and included only age and the Box and Block Test for the hemiplegic hand. The model developed to explain variation in the Physical Health Summary Score of women did less well, with an r^2 of 0.34. The

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[9] Two variables with a Pearson Correlation Coefficient of higher than 0.80 were considered to be "highly correlated."

[10] Because the models were being developed partially to estimate quality of life in non-communicative individuals, they were not adjusted for any variables requiring patient self-report.

TABLE 5.7

Parameter estimates for performance variables and selected confounders derived from simple linear regression on the Physical and Mental Health Summary Scores

Variable		Physical Health Summary Score		Mental Health Summary Score+	
		Parameter Estimate (ß)	Standard Error (SE)	Parameter Estimate (ß)	Standard Error (SE)
OARS IADL		*1.73	0.47	*120.65	48.02
Barthel Index:	100/100	ref.	-	ref.	-
	Less than 100	*-10.06	3.21	*-742.20	318.08
Timed Up and Go		*-0.52	0.17	-25.12	17.19
Box & Block Test, Hemiplegic Hand		*0.28	0.08	5.97	8.79
Box & Block Test, Normal Hand		*0.31	0.12	*23.93	11.41
Albert's Test:	1 or more errors	ref.	-	ref.	-
	0 errors	3.23	3.56	289.34	338.53
Chedoke-McMaster Stroke Assessment		*1.11	0.31	-18.99	33.75
Geriatric Depression Scale		*-0.69	0.31	*-116.95	24.81
Age		-0.24	0.16	1.17	15.67
Gender:	Men	ref.	-	ref.	-
	Women	-1.33	3.45	-316.80	324.66
Support:	Lives Alone	ref.	-	ref.	-
	Not Living Alone	1.25	4.44	-248.86	419.90
Charlson:	2 or more comorbidities	ref.	-	ref.	-
	0 or 1 comorbidities	3.32	3.39	18.14	325.24
Transition Item:	Health worse	ref.	-	ref.	-
	Health better or same	*7.73	3.41	643.95	328.38

*indicates statistically significant association, $p<0.05$, based on t-statistic ß/SE; ref.=referent, parameter estimate = 0.

+ = Mental Summary Score Squared, therefore ß's and SE's are for MCS^2

TABLE 5.8

Parameter estimates for performance variables derived from simple linear regression on the Physical and Mental Health Summary Scores by gender

Variable	Physical Health Summary Score				Mental Health Summary Score+			
	Women		Men		Women		Men	
	ß	SE	ß	SE	ß	SE	ß	SE
OARS IADL	*1.79	0.77	*1.70	0.64	*227.66	63.02	-32.07	67.22
Barthel Index: 100/100	ref.	-	ref.	-	ref.	-	ref.	-
Less than 100	-10.03	5.80	*-11.14	3.98	*-1289.46	507.53	-103.03	427.03
Timed Up and Go	*-0.44	0.24	*-0.87	0.30	-42.41	22.71	42.71	31.57
Box & Block Test, Hemiplegic Hand	0.27	0.15	*0.36	0.10	17.19	15.48	-9.27	11.34
Box & Block Test, Normal Hand	0.27	0.22	*0.46	0.15	*53.21	17.58	-7.53	16.20
Albert's Test: 1 or more errors	ref.	-	ref.	-				
0 errors	8.90	6.04	-1.75	4.37	126.06	614.30	365.57	399.49
Chedoke-McMaster Stroke Assessment	*1.30	0.55	*1.01	0.38	8.74	61.15	-54.73	38.98

*indicates statistically significant association, p<0.05, based on t-statistic ß/SE
ß=parameter estimate, the rate of change Y with respect to X
SE=standard Error
+ = Mental Summary Score Squared, therefore ß's and SE's are for MCS^2

Table 5.9

Parameter estimates for men's and women's best models to explain Mental and Physical Summary Scores of the SF-36.

	Parameter Estimate	Standard Error	T-value (p)
Women's Models			
Physical Health Summary Score Model r^2=.34			
Intercept	23.89	30.30	0.79 (0.44)
Chedoke-McMaster Stroke Assessment Scale	1.06	0.57	1.88 (0.08)
Age	-0.31	0.23	-1.34 (0.20)
+Mental Health Summary Score Model r^2=0.66			
Intercept	2274.12	2190.12	1.04 (0.32)
OARS IADL Index*	392.61	77.71	5.05 (0.00)
Chedoke-McMaster Stroke Assessment Scale*	-148.76	48.40	-3.07 (0.01)
Age	23.13	19.00	1.22 (0.24)
Men's Model			
Physical Health Summary Score Model r^2=0.39			
Intercept	2.90	18.00	0.16 (0.87)
Box and Block Test, hemiplegic hand*	0.41	0.11	3.73 (0.00)
Age	0.23	0.20	1.14 (0.27)

*=significant independent predictor

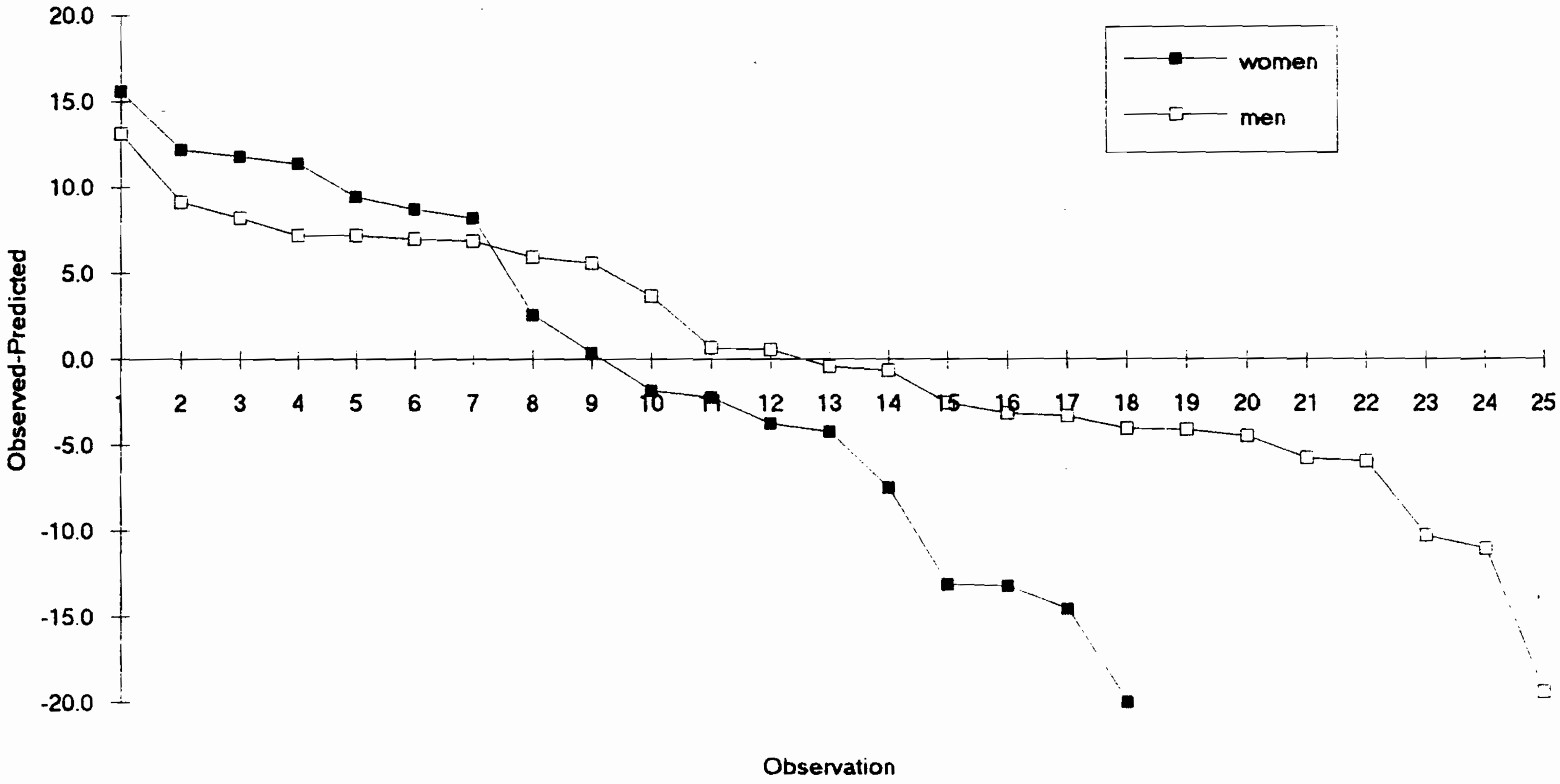
+=*Squared* Mental Health Summary Score

Chedoke-McMaster Stroke Assessment Scale, Impairment Inventory, and age made up the model, although neither factor was a significant independent predictor. No performance-based variable or combination thereof could predict the Mental Health Summary Score for men. Thus, no model for men's mental health has been included.

In order to determine how well the models would perform if they were required to estimate quality of life in a population who could not complete quality-of-life questionnaires or interviews, predicted values from each of the models were generated. The amount of error, or residual value, is the difference between the observed value and the predicted value. Residual values were determined, sorted in descending order, and plotted on graphs 5.2 and 5.3 to demonstrate the accuracy of the models. Graph 5.2 shows the residuals from the squared Mental Health Summary Score model for women. The Physical Health Summary Score models for women and men are compared in Graph 5.3. In that example, the more accurate men's model produces a plot that lies closer to the line of zero error through the middle range.

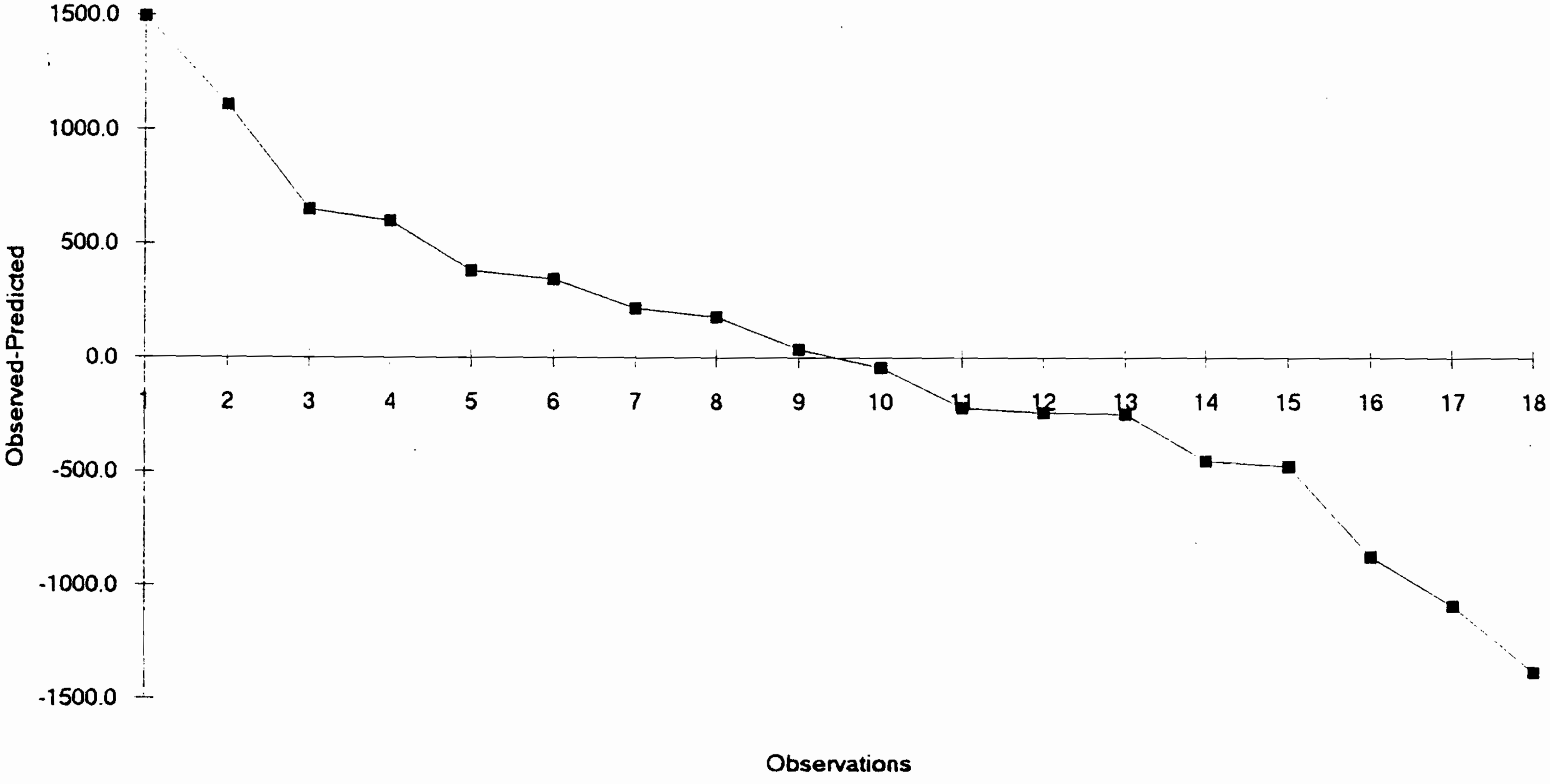
Graph 5.2

Residual values for men's and women's Physical Health Summary Score models



Graph 5.3

Residual values for women's squared Mental Health Summary Score model



5.7 Summary

The main results from the study have been presented in this chapter. The sample was described in terms of key medical chart-derived characteristics and compared to the non-participants from the study population. No differences were found between the two groups. Similarly, results from French questionnaires were compared to results from English questionnaires, and the mean values were not different. Therefore, the data from the French and English subjects were pooled.

The sample was then described in terms of the study variables. Descriptive statistics for the SF-36 and the performance-based measures were presented. Of the eight subscales on the SF-36, the sample scored the lowest on Physical Role Limitations (49.4/100.0) and the highest on Social Functioning (80.1/100.0). The mean Physical Health Summary Score (41.1) was much lower than the mean Mental Health Summary Score (52.2), as well as being lower than the normal United States population mean of 50.0. In terms of the performance-based measures, the means were all close to the optimal scores.

Univariate associations between the independent variables and the two Summary Scores of the SF-36 were determined. Several performance-based measures were significant predictors of mental and physical health. However, in order to see the effects of combinations of variables together, multivariate analyses were conducted. Because of strong interactions between some variables and gender, specific models were developed for men and women. Physical health of men was best predicted by the Box and Block Test for the hemiplegic hand adjusted for age. The OARS IADL Index and the Chedoke-McMaster Stroke Assessment Scale, Impairment Inventory adjusted for age accounted for 66% of the variation in the mental health scores of women. The other models performed less well. No performance measure or combination of performance measures could predict the mental health of men, and the Chedoke McMaster Stroke Assessment combined with age accounted for only 34% of the variation in the Physical Health Summary Score of women.

In the following chapter the meanings of these results with respect to the study questions will be explored.

6.0 DISCUSSION

6.1 Introduction

The objective of this study was to determine which performance-based measures correlate highly with health-related quality of life in persons with stroke. That objective was met by determining univariate associations, as well as by constructing multivariate models to illustrate the interrelationships amongst the performance measures. The following discussion puts forth answers to the questions raised in Chapter Three. Subsequently, issues raised in the literature review about the quality of life in stroke are discussed. Next, limitations of the study and potential sources of error are examined. Finally, the relevance of this project is presented, and suggestions for future studies are made.

6.2 Discussion of the Specific Study Questions

6.2.1 Can a measure that relies on the actual performance of tasks be used to predict some or all of the components of health-related quality of life?

A combination of measures that rely on the actual performance of tasks were able to predict the mental and physical health components of health-related quality of life, as measured by the SF-36, in this particular sample. However, interesting gender differences appeared in the predictive models. The specific measures that predicted each aspect of health-related quality of life for both men and women are discussed in the following paragraph. Pursuant to that, the potential reasons for differences between men and women are examined. Finally, the usefulness of the models to detect quality of life in groups versus individuals is discussed.

For women, portions of both the mental and physical components of health-related quality of life, as measured by the SF-36, were explained using performance-based tasks. In the case of men, only the physical health component was well-explained. No statistically significant model containing only performance-variables was developed for Mental Health Summary Score in men. Although each performance variable was a significant predictor of either mental or physical health in simple regression modeling, when multiple variables were included in gender specific models, only three variables emerged. Those were the OARS IADL Index, predicting the Mental Health Summary Score of women, the Box and Block Test for the hemiplegic hand, predicting the Physical Health Summary Score of men, and the Chedoke-McMaster Stroke Assessment Scale -- Impairment Inventory, predicting the Physical Health Summary Score and the Mental Health Summary Score of women.

The Physical Health Summary Score for men was best predicted by the sensitive Box and Block Test for the hemiplegic hand. The best tool to predict the physical health of women was the Chedoke-McMaster Stroke Assessment Scale, Impairment Inventory. The OARS IADL Scale was clearly the strongest predictor of women's mental health, although the Chedoke-McMaster Impairment Inventory also contributed.

The direction in which the Chedoke-McMaster Stroke Assessment Scale Impairment Inventory predicted the mental health of women deserves comment. The parameter estimate was negative, even when used as a categorical variable. The implication is that a woman's mental health status deteriorated as her impairment level improved, given that she was as capable as another with her instrumental activities of daily living. Intuitively, one would expect mental health status to improve concomitantly with neurological recovery. It is possible that this finding is strictly due to chance, and to ascertain that requires the study be replicated. If not a random occurrence, then one must ask why the women who had lower levels of neurological recovery reported higher levels of mental health. Perhaps those who have apparent neurological deficits are pleased with themselves that they are capable of dwelling in the community, despite their impairments. Recall that the degree of motor recovery only predicted negatively when adjusted for instrumental activities of daily living, which had a strong positive association. Another point to consider is that the Chedoke-McMaster Stroke Assessment Scale, Impairment Inventory was the only performance measure that appeared in the model to predict the physical health of women, and in that case the direction of association was as expected - those women with better neurological recovery reported higher levels of physical health. It appears that although the women may be attaching a lot of importance to the impairment level of disablement, the strongest indicator of their true feelings is their ability to perform instrumental activities of daily living. Two women with residual motor deficits might see their health status in the following way. The first woman might report that physically, she is doing very badly. Despite that, she can still go out and do her own banking and grocery shopping, therefore, mentally, she reports that she is doing very well. The second woman with residual motor deficits would likely also report decreased physical health. However, for some reason, she is unable to manage her own finances, thus reports reduced mental health. Women's mental health status, in this post-stroke sample, is largely dependent on their capability in instrumental activities of daily living.

In terms of the gender differences, one must ask why the mental health score of men can't be estimated, or conversely, since physical performance measures were used, why can the mental health of women be predicted so accurately? Why do different performance measures predict better for men than for women? The average Physical Summary Scores for men and women were similar (41.7 and 41.2, respectively), however the mean Mental Summary Score for women showed a trend towards being lower than that of men (50.4 compared to 54.0). In the normative values published by Ware, 1994, women's mental health scores are always slightly lower than males of the same age. Furthermore, other authors have found that women are more likely than men to be depressed post-stroke (Bacher et al., 1990). If women are reporting worse mental health, and the poor mental health can be explained by diminished ability on performance-based tasks, perhaps the explanation is simply that women are more self-aware, and as such have closer links between their physical and mental well-being. It is possible, that by chance, the women were physically different from the men. Post-hoc analysis of mean performance variable scores revealed that the women scored significantly lower on the hemiplegic hand Box and Block Test, but otherwise they were not different. Thus, the gender difference can't be explained by the severity of physical impairments and disabilities.

Gender difference in the impact of stroke have been found previously. In addition to the findings about depression described earlier, Wood-Dauphinee and colleagues (1984) found that women benefited less from team care following a stroke than did men. These gender differences in treatment and recovery post-stroke is an area that warrants further investigation.

For all regression models developed, the residual values were roughly evenly distributed between overestimation and underestimation, as can be seen in Graphs 5.2 and 5.3. Although there was substantial error in predicting SF-36 scores of individuals, the total of the residual values approximates zero. Thus, for estimation of the mean score of groups, the regression models are relatively precise. If one used a regression model to predict quality of life in an individual, there would be a high chance of error. However, to estimate the quality of life in a group, it would probably be quite accurate.

Two recently published studies examined the association between self-administered or self-preceived physical function scales and physical performance measures, and reported varying results. Reuben and colleagues (1995) examined the associations between four self-administered or interview-administered physical function scales, the SF-36, and a performance-based ADL measure, the Physical Performance Test (Reuben and Siu, 1990) in 83 community-dwelling elderly persons. Using mostly univariate correlations, they concluded that the relationships between different ways of measuring similar constructs were weak and inconsistent. These investigators did not appear to have examined the effects of age or gender. Cress and colleagues (1995) compared results from the SIP's physical dimension summary score with various measures of physical performance, including gait speed and maximal grip strength. They reported gait speed to be the single greatest predictor of physical function in both community-dwelling and nursing home residents, even when symptoms of depression were taken into account. This group of investigators used multiple regression analysis in order to see the combined effects of variables. Their conclusion, in contrast to that of the Reuben study, was that a combination of performance variables could predict physical health status relatively well.

To summarize the answer to the foremost question, yes, physical performance measures may be useful in predicting physical health-related quality of life in both genders, and may even predict mental health-related quality of life in women. The error margin for individual values was large, but for estimating group effects the regression equations were accurate. The potential impact for rehabilitation clinicians and researchers is two-fold. Firstly, it may be that using performance-based measures gives a more accurate estimate of health-related quality of life in non-communicative individuals than proxies, and that such a system may be useful to rehabilitation professionals to assess these individuals. As cited previously, using predictive models is a better system to be used with groups rather than individuals. However, in view of the poor performance of proxies (Pierre et al., 1995), a model may be the only choice, even for individual cases. The second potential impact for rehabilitation professionals is the clear link between physical impairment and disability and both physical and mental health-related quality of life. Even though quality of life itself is rarely measured in rehabilitation institutions, the results of performance tasks are. The findings of this study indicate that poor performance on a variety of tasks may be extrapolated to indicate poor quality of life. Due to the limitations of this study, it remains unclear whether or not improved or diminished performance over time would alter the individuals reported quality of life.

6.2.2 Are performance-based disabilities more strongly correlated with quality of life than performance-based impairment measures?

The differences between impairments and disabilities were discussed in Chapter 2. By strict definition, most of the measures used were disability measures. However, practically speaking only the Barthel Index and the OARS IADL Index were true disability measures, the Chedoke-McMaster Stroke Assessment Scale, Impairment Inventory, was the only measure that uniquely reflected an impairment, and the others fell somewhere in the middle. A disability is defined as the restriction or lack of ability to perform an activity due to impairments, whereas an impairment is a loss or abnormality of psychological, physiological or anatomical structure. The classification debate would examine whether the activities in the Timed Up and Go, the Box and Block Test, and Albert's Test more reflected functional tasks or physiological impairments. I feel that Albert's Test, because it measures perceptual hemi-neglect fairly specifically, approximates an impairment measure, whereas the other two more resemble disability measures because of the increased complexity of the tasks.

The International Classification of Impairments, Disabilities, and Handicaps, (ICIDH) as implicated by the title, contains a third class of disablement that was not addressed in this study. Handicap, even by the admission of the World Health Organization in the introduction to the 1993 version of the ICIDH manual, is problematic. Overlaps exist, between disability and handicap, as well as between disability and impairment. However, the former distinction is the most vague, and is particularly unclear with respect to functional limitations and activities of daily living. The 1993 ICIDH manual also states that handicap is not a classification of individuals, but rather a classification of circumstances in which disabled people are likely to find themselves, that place them at a disadvantage relative to their peers. The distinction between handicap and the concept of quality of life is also nebulous. Jette (1994) reviewed the ICIDH and compared it to the Nagi classification scheme (Nagi, 1965, 1991), and discussed modifications to both concepts. Most notable was the idea of including quality of life in the model, overlapping with handicap and functional limitation[11]. Considering the problems with gaining a comprehensible notion of the classification of handicap, it was not evaluated. Rather, quality of life was postulated to encompass handicap, and our interest lay with the ability of the more fundamental classes of impairment and disability to predict the broad, patient-perceived concept of health-related quality of life.

Having said that, let us return to the question. Both impairment (Chedoke-McMaster Stroke Assessment Impairment Inventory) and disability measures (OARS IADL, and the Box and Block Test) appeared in the multivariate regression equations as independent age-adjusted predictors of Physical or Mental quality of life. The measures are all very closely interrelated, so disassociating them is difficult. Also, a very limited number of the full range of impairments was measured. It was hypothesized that disability measures would predict better than impairment measures, as it seems logical that most persons with stroke would be more concerned with the functional effect of an impairment than the impairment itself. An individual is more likely to complain that he is unable to place items on high shelves than that his arm is weak. However, the functional questions in ADL scales often do not go far enough. For example, subject number five scored 95 on the Barthel Index, but only 14.2 on the SF-36's Physical Health Summary Score. In her case, the low score was explained more by impairment measures - 33 on the Chedoke-McMaster Stroke Assessment Scale Impairment Inventory, indicating incomplete neurological recovery. Although this woman was able to feed herself independently, she complained that it took her an entire afternoon to peel potatoes. Most ADL scales are not sensitive to such issues. In fact, the only independent predictor of the physical health of women was the Chedoke-McMaster Stroke Assessment Scale -- Impairment Inventory.

Although disabilities may be more important to the individual, those disabilities are caused by impairments. Many of the disability scales which are currently in use have a

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[11] "Functional Limitation" in the Nagi scheme, is similar to "Disability" from the ICIDH model.

surprisingly low ceiling in community-dwelling persons, and it would be difficult to design a scale that captured all of the potential functional limitations. Thus, the impairment measures detect subtle problems, and a self-reported health status measure can then determine how much the person is effected by that impairment. Furthermore, disability tests such as the Box and Block Test, which have the added challenge of a speed component, also aid in detecting diminished quality of life missed by the ADL scales. In addition, upper extremity function is an important predictor of health status. A study by de Haan, Horn, et al. (1993), found that at the level of handicap and quality of life, arm and hand motor function became important, whereas in the case of disability measured by the Barthel Index, leg function was more explanatory. They note that the Barthel Index tends to emphasize the mobility aspects of daily living rather than the upper limb function. Both the Box and Block Test and the Chedoke-McMaster Stroke Assessment Scale, Impairment Inventory, reflect hand and arm function.

It appears that, in this sample, using the particular instruments selected for this study, that the impairment and disability measures are both required to predict health-related quality of life. This finding is similar to results reported in the study by de Haan, Horn, et al. (1993), who compared five stroke impairment scales with a measures of disability (Barthel Index), handicap (Rankin Scale), and quality of life (Sickness Impact Profile). They reported that impairment only partially explained quality of life, and that there seemed to be a hierarchical structure of the ICIDH, with impairments correlated most strongly with disability, and disability strongly correlated with handicap and quality of life. Rehabilitation clinicians are encouraged to continue using a wide battery of assessment tools in order to obtain a thorough portrait of the patient or subject involved. Due to the ceiling and floor effects in many disability scales, the more responsive impairment and disability tests are necessary to draw a complete picture of quality of life.

6.3 Comparison of Results to Previous Studies.

In the literature review, several important points about the state of the art of quality of life research in stroke patients were discussed. In this section, the results of this study will be compared to previous findings. The overall health-related quality of life of the sample will be discussed with respect to what other authors have found. The number of people excluded due to communication or cognitive problems will then be discussed. Finally, the associations found between performance-based measures and quality of life in this study will be contrasted to the findings in other studies.

Previously published studies about the quality of life in stroke patients have found that stroke survivors have a lower quality of life than the general population (Åström, Adolfsson et al., 1992; Åström, Asplund, Åström, 1992; Ebrahim et al., 1986; Viitanen et al., 1988), that post-stroke quality of life is lower than that in the pre-stroke period (Johansson et al., 1992; Lawrence and Christie, 1979; Niemi et al., 1988; Viitanen et al., 1988), that quality of life may continue to deteriorate with time (Åström, Asplund, Åström., 1992; Nydevik and Hulter-Asberg, 1992). The cross-sectional nature of this study does not allow any insight into the participants' past or future quality of lives. Furthermore, it was not designed to compare the participants to the general population. However, Ware (1994) published normative values for the general United States population for the Mental Health and Physical Health Summary Scores. It is interesting to note that the Physical Health Summary Scores, for both men and women, are significantly lower than the general United States population, in agreement with the other studies. For largest age group of individuals between 65 and 74 (n=15), the stroke patient's Physical Health Summary Scores were significantly lower than the normal values for that age group, despite the very small sample size. A full comparison of this sample to United States population normative values can be found in Appendix E.

In the previously published studies, between 10% and 27% of potential participants were excluded because they could not complete quality of life interviews. Of the 60 people actually contacted to participate in the study, 10% (6) were excluded because they were unable to do the telephone interview. This number is similar to that seen in other studies, but at the low end of the range. That low percentage is likely because of the timing at one-year post stroke. Studies which followed people with stroke from the onset would have many more non-communicative individuals. In this case, many of the severely impaired people were probably deceased by one year, and others may have improved enough to participate.

A number of problems with determining the associations between performance-measured impairments and disabilities and quality of life were discussed in the literature review. Those problems included the exclusion of many of the performance-based variables, the categorization of many variables, and the almost exclusive use of univariate statistical analyses. The result was that poor health-related quality of life remained unexplained in a large portion of individuals.

Many important physical performance measures, as yet unstudied with respect to quality of life in stroke, were examined in this project. All of those instruments were significant in at least one of the simple regression equations, and four of them appeared in the multivariate equations. Thus, it is apparent that factors other than independence in basic activities of daily living are associated with both the physical and mental quality of life of stroke survivors. One of the problems with the using activities of daily living to predict quality of life in community dwelling individuals is that most of them are independent with those tasks. The median value for the Barthel Index in this study was 100, indicating that at least half of the sample achieved a perfect score. And yet, many of these people reported a lower Physical Health Summary Score than the general population. This problem, of people independent with their activities of daily living scoring low quality of life, was reported by Lawrence and Christie (1979), Ahlsio and colleagues (1984), Viitanen and colleagues (1988), and Åström, Adolfsson and colleagues (1992). Many of those investigators dichotomized activities of daily living to either "dependent" or "independent". Similar results were seen in this study, and the Barthel Index had to be dichotomized once again, as it was extremely skewed to the high end of the scale. The problem lies in the ceiling effect and lack of sensitivity in the tools used, and in the limitations of univariate analyses.

In this study, however, the use of a range of impairment and disability measures, the use of continuous or multiple level ordinal scales, and the employment of multivariate analysis techniques allowed for the development of models which explained significant amounts of the variation in health-related quality of life. One of the useful tools was the Box and Block Test, which appeared in the regression equation for the physical health of men, in addition to the Barthel Index. In this population, the Box and Block Test did not have a ceiling effect, the scoring ranged from very low to quite high. However, the stroke sample scores were lower than the published normative values, even for the non-affected hand. Thus, perhaps the men who achieved high scores on the Barthel Index, yet low Physical Health Summary Scores had subtle physical deficits that required more sensitive tools, such as the Box and Block Test, in order to be detected. For example, 38 people out of the 44 who responded to the Barthel Index scored 90, 95, or 100. With the Box and Block Test for the unaffected hand, only eight people scored 70 or higher, which is the approximate normal population mean value for the older age groups. For the affected hand, only four scored 70 or higher.

This study has provided information to help fill in some of the important gaps that exist in the current state of the literature regarding the quality of life of stroke patients. It has been demonstrated that associations exist between many impairment and disability variables in addition to status in activities of daily living. As well, it appears that multivariate analysis and the use of sensitive, multiple-level measures can explain large amounts of the variation in health-related quality of life.

6.4 Study Limitations and Potential Sources of Bias

Any research is subject to error, which may be random or systematic. Random error is assumed to nullify itself by being equally distributed between above and below the *truth*. Systematic error, on the other hand, is unidirectional, and leads to a deviation from the truth in the outcome. Systematic error is also known as *bias*, and may occur at any of the following stages of research: reading up on the field, specifying and selecting the study sample, executing the experimental manoeuvre, measuring the exposures and outcomes, analyzing the data, the interpreting the analysis, and publishing the results (Sackett, 1979). The biases involved in reading up and publishing often, but not always, involve subtleties of opinion held by the author. Thus, for the author, they are usually difficult to detect, and as such will not be discussed in depth. Suffice it to say that the literature review and analysis were done with an open mind, but there is little doubt that some undetected bias exists from those sources. No experimental manoeuvre was performed in this parameter estimating study, thus, that source of bias was eliminated. Potential sources of bias at the other stages of the project are discussed in the following paragraphs. The power of the study to detect the desired effect size is also discussed.

The problem of bias in sampling is a frequent and difficult one (Sackett, 1979). The target population for this study was all community dwelling people with stroke. The study population is an adequately-sized group of people who have met the inclusion criteria. The study population must be representative of the target population. For this project the study population was made up of those eligible people with stroke who were admitted to the Montreal General Hospital between August 1993 and August 1994. It could be argued that the study population is not representative of the target population, since all individuals came from the same hospital. Often, using only one hospital from a big city may introduce a geographic, economic, or another less obvious bias to the sample. However, the Montreal General Hospital is a large, university teaching hospital which draws people from all over the city. As well, stroke is often an emergency situation, and most individuals aren't able to choose to go to a particular hospital. Thus, it was felt that the people admitted to the Montreal General Hospital for stroke would represent a fair cross-section of the population.

In clinical studies where it is often theoretically possible to select the whole population, selection bias may occur when there is a high rate of refusal. In this project, of the 51 people eligible to participate, only 6 refused. This represents a response rate of greater than the 80% required by convention to decrease non-respondent bias (Sackett, 1979).

Measurement bias is easier to prevent than sampling bias (Sackett, 1979). Strategies such as using standardized scales with good psychometric properties and having the home assessor blind to the results of the telephone interview were used in this study to minimize systematic measurement error. However, the use of two different language versions of many of the scales is a major potential source of measurement bias. Having both a French and an English version of the scales was necessary because there are two predominant languages in Montreal. Whenever different versions of the same scales are used within the same population, there is concern that they may be different enough to bias results. Prior to beginning the study, steps were taken to reduce the likelihood. Whenever possible, officially translated versions of the scales were used. If there was no official French version, as was the case for the Geriatric Depression Scale and the OARS IADL Scale, they were translated and back-translated by two different, licensed translators. The two English versions were then compared for accuracy, and any discrepancies were adjusted in the final French version. As well, the two language groups were tested post-hoc using Chi-square analysis to ensure there was no statistically significant difference between them. There were no differences, nor did there appear to be trends towards differences. Results from both language versions of the scales were then pooled for the remainder of the analysis. Although there may be differences in the scales which are undetectable with this small sample size, it is felt the discrepancies were negligible.

Another potential source of bias stems from the analysis. The models were not adjusted for effect of some potential confounders. Notably, depression and pre-stroke health status were not used in the multivariate regression analysis. The reason is that they are patient self-reported variables, and thus would not be useful in a performance-based model to estimate quality of life in non-communicative individuals. However, it is interesting to note that the Geriatric Depression Scale Score and pre-stroke self-reported health status were both crudely associated with the Physical Health Summary Scale. None-the-less, much of the variation in health-related quality of life was explained by performance-measures alone.

Often plaguing research is the problem of lack of power. The power of the study is the probability of achieving significant results, and is a factor of the variance of the variables involved, the sample size, as well as the size of effect one desires to detect. The sample size was pre-determined at 50 subjects to have 90% power to detect correlations as low as $r=0.45$, including an allowance for multiple independent variables. Thus, the sample size was large enough to detect the desired associations, and power was not a limitation of this study as it was designed. However, a larger sample size would have allowed for the inclusion of other potentially important variables in the models. As well, the unexpected division of the sample by gender reduced the power. Again, the most notable effect is a reduction in the number of variables which can be included in the models.

Although this study had limitations, and certain results should be interpreted cautiously, it is felt that a contribution to knowledge about quality of life in stroke patients has been made. It is hoped that the problems and concerns can be addressed in future studies.

6.5 Statistical Considerations

A number of assumptions were made for the univariate and multivariate analysis. According to Kleinbaum, Kupper, and Muller (1988), the assumptions for regression analysis are existence, independence, linearity, homoscedasticity, and normality. Each of these will be discussed in the context to these particular data.

Existence implies that for each combination of X, or independent variables, Y, or the outcome, is a random variable with a certain probability distribution having finite mean and variance. This first entity is truly an assumption, and is difficult to verify.

Independence implies that the Y values are statistically independent from one another. Moore and McCabe (1993) define independence as follows: "events A and B are independent if knowing whether A occurs does not change the probability that B occurs." For these data, the outcome responses are independent. Knowing the results of one patient's response to the SF-36 does not influence another's response, since they are all separate people with their own particular set of circumstances. An example of *dependent* outcomes would be individuals within the same household answering the same questionnaires.

Linearity assumes that the mean value of Y for each combination of X variables is a linear function of each X, that is to say the general regression equation,

$$Yi = \beta i_0 + \beta i_1 Xi_1 + \beta i_2 Xi_2 + \ldots + \beta i_p Xi_p + \text{Error}$$

holds true. "E" is the error component of the model, and represents the difference between an individuals observed response and the truth. Prior to beginning the regression analysis, the linearity of each performance variable with both the Physical and Mental Health Summary Scores was examined in simple plots with the quality of life variable on the Y-axis and the performance measure on the X-axis (Appendix F). The extreme skewing of both the Barthel Index and Albert's Test towards the optimal ends of the scales led to the dichotomization of those variables, in order to protect the assumption of linearity. The linearity of the final models was checked using residual analysis. The residual values, representing the difference between the observed and the predicted values, are plotted against the predicted values. These graphs are shown in Appendix G. There is no definitive evidence of non-linearity.

Homoscedasticity, that the variance of Y is the same for any fixed combination of X variables, is the fourth assumption. In two of the residual plots, the Physical Health model for men, and the Mental Health model for women, there appears to be a tendency for the residual values to increase at the same time as the predicted values increase. This would indicate some heteroscedasticity in the data. The small sample size makes the diagnosis impossible. If, however, the trend were to be replicated with a larger data set, it would indicate that the model is increasingly inaccurate as the predicted health-related quality of life improves. If that is the case, it is very likely that additional variables, or more complex models, need to be considered.

The fifth, and final assumption for multiple linear regression, is that of normality. It is assumed that, for any fixed combination of X variables, the variable Y is normally distributed. Kleinbaum, Kupper, and Muller (1988) state that the usual tests of hypotheses used in regression analysis are robust enough that only extremely abnormal distributions lead to spurious results. None-the-less, the Mental Health Summary Score was found to have a non-normal distribution for both men and women, and was transformed to its squared form in order to normalize it. Other transformations considered were its natural logarithm, base 10 logarithm, and its inverse form. Only the squared Mental Health Summary Score produced a Gaussian distribution.

Violations of any of the assumptions of multiple linear regression can lead to biased results. It is impossible to categorically state that, in this case, the assumptions have all held true. However, precautions were taken to ensure that they have. It is safe to say that there were no apparent violations, even when they were specifically sought. It is possible that the variance in the outcomes, the Physical and Mental Health Summary Scores, is not the same for all X values. The implication of such a problem is that the model may become increasingly inaccurate as the health status scores improve. That could certainly lead to misinterpretation of the associations between physical performance measures and those who report high quality of life. Future investigations should examine the variance with care. Overall, it is felt that the assumptions were well-met.

6.6 Contributions and Suggestions for Further Studies.

This study had several aims. Along with answering the specific study questions, which were discussed previously, it was hoped that the conceptualization of quality of life and its relation to the International Classification of Impairments, Disabilities, and Handicaps would be improved, and that the associations determined would generate hypotheses for future longitudinal studies. I am optimistic that some of the information from this project will be clinically relevant, and helpful to rehabilitation professionals.

In terms of the conceptualization of health-related quality of life and its relation to the International Classification of Impairments, Disabilities, and Handicaps, it is clear that both the mental and physical components are associated with the impairments and disabilities estimated in this study. It remains unclear as to whether one level of disablement is a stronger predictor than the other, and the involvement of handicap was not examined as such. However, the strongest independent predictor to emerge was the OARS IADL Scale for women's mental health, clearly a higher order disablement - a disability, or perhaps even a handicap. It is likely that there is a hierarchy of association as observed by de Haan, Horn, et al. (1993), but, as the impairments become more subtle, the disabilities and handicaps they effect become more high level. Often, our scales are incapable of detecting them.

Although it was not expected that physical performance measures could predict the mental aspect of health-related quality of life, in the case of women it was possible. Women had a lower mean Mental Health Summary Score than did men, and their scores were well predicted with a combination of performance measures. Does this reflect a closer association between physical and mental well-being in women? Are women more self-aware, or simply more prone to diminished self-perceived mental health? The answers to the gender differences remain unapparent.

Another concept that has emerged is that of independence in activities of daily living being insufficient in itself to explain good health-related quality of life. In this sample, additional variation in the health-related quality of life was explained by using more sensitive tools in addition to or instead of the Barthel Index. For example, the Box and Block Test for the hemiplegic hand appeared in the model for physical health of men. Women's mental health was better explained by instrumental activities of daily living than by basic activities of daily living, and women's physical health was explained by an impairment measure. It is probably not enough for most people to be independent with basic tasks such as feeding and dressing. Rather, the quality of their movements is also important for quality of life. Good manual dexterity is required for almost every task during the day, including many hobbies such as baking or woodworking. Furthermore, manual dexterity may be an independent predictor of mortality. Williams and colleagues (1994) reported that poor scores on a timed test of manual performance predicted hospitalization and mortality two years later, even when adjusted for age, gender, race, and number of prescribed medications. Higher level mobility, both of the upper and lower extremity, is required to perform instrumental activities of daily living, such as shopping and banking. Hoxie and Rubenstein (1994) studied 592 older pedestrians crossing an intersection, and found that 27% of them were unable to cross in the time allotted. They reported that a near normal gait speed is required to cross in time, and that some older people do not cross the intersection as often as they would like to out of fear. A recent discussion article by Radomski (1995), aptly entitled "There is more to life than putting on your pants," discusses quality of life of rehabilitation patients. She stresses that occupational therapists (and, I hasten to add, *all* rehabilitation professionals) need to look behond simple recovery, and focus treatment on social, leisure, and productive activities that make life worth living. One method to consider might be an increased emphasis on out-patient programming.

It is safe to say that manual dexterity and IADL have been neglected in the past as predictors of diminished quality of life of stroke patients, as they were not examined in any of the studies reviewed in Chapter Two. In the study by Williams et al. (1994), both were independent predictors of death. De Haan, Horn, and colleagues (1993) found strong associations between arm and hand function and the higher order disablements of handicap and quality of life. In this study, IADL was the strongest independent predictor for women's mental health-related quality of life; and manual dexterity was the strongest independent predictor for men's physical health-related quality of life. Hand function and function in instrumental activities of daily living appear to effectively reflect health status in people who have survived a stroke. Thus, they must be addressed in treatment and follow-up of stroke patients, as well as in future research. Independence in activities of daily living is *not* an adequate indicator of good health-related quality of life.

The knowledge gleaned from this study generates numerous ideas for future research. As well as being necessary to test the models developed here, and to attempt to replicate the associations, it is also imperative that we progress to longitudinal studies to determine the causality of poor quality of life, and to evaluate the effects of new and old interventions on the health status of people with stroke. Furthermore, it is necessary to investigate why women and men with stroke perceive their health status differently.

If these models were to be used to approximate quality of life, it would be mandatory to test them further. The ability of the models to estimate quality of life at different times post-stroke, to detect changes in health status, or simply to be accurate in a different sample must be scrutinized. As well, it would be advisable to compare their accuracy in predicting quality of life to that of proxies.

This study was limited by its cross-sectional nature, in that causality could not be determined. Although it seems logical that reduced physical performance leads to diminished self-perceived physical quality of life, it is impossible to determine without taking measurements over time, and without having some estimate of pre-stroke status. A long-term follow-up study is required to determine the changes in associations between performance-based measures and quality of life over time.

Future studies about the burden of stroke should focus on discovering the causality of poor quality of life post-stroke. They should also attempt to clarify the differences in the quality of life of men and women.

Possible interventions to be considered in the future might include an increased focus on manual dexterity in the rehabilitation setting by physical and occupational therapists, and longer term follow-up in the home setting. The people who go home without rehabilitation might require better access to therapeutic consultants to smooth their transition and provide them with advice on specific problems encountered in their own surroundings. Although these individuals at one year post-stroke were doing well in the larger sense, that is to say they were living independently in the community, many of them exhibited physical problems that need to be addressed. Interventions directed at improving the performance of people with stroke in their home environment might improve their health status, and diminish the burden on the health-care system.

Will any of this information be immediately relevant to rehabilitation clinicians? Certainly, if one considers the importance of health-related quality of life in terms of its ability to predict mortality, it is directly applicable to physical and occupational therapists that strong associations exist between those impairments and disabilities they regularly treat and the patients overall health status. That is to say, the results emphasize the importance of their treatments. Furthermore, it is evident that rehabilitation goals, particularly in community-based rather than institution-based medicine, must go beyond basic independence in activities of daily living. For most people, it is simply not enough to return to their home with the ability to walk slowly, bath, dress, and feed themselves. The participants in this study expressed the desire to be able to do things such as travel out of town, do their own foot care, or even play tennis! Rehabilitation professionals are urged once again to collaborate with the patient on treatment goals, and to help the patient achieve more than a minimum level of function. The health-care system is implored to search for ways to improve the quality of life of stroke patients within the new economic constraints.

6.7 Conclusion

This project was initiated with the objective of determining which performance-based measures correlate highly with health-related quality of life as reported by community-dwelling people one year post-stroke. To complete that objective, a two part cross-sectional study of 45 individuals one year post-stroke was conducted. Quality of life, activities of daily living, and instrumental activities of daily living were assessed by telephone interview; gait status, stage of neurological motor recovery, gross manual dexterity, and perceptual hemi-neglect were evaluated at the subject's home by a physiotherapist.

The study sample reported quality of life that was lower than population normative values for some subsections of the SF-36: General Health, Physical Functioning, Role Limitations due to Physical Problems, and the Physical Health Summary Score. Despite that, the mean and median scores for most of the performance measures were towards the optimal ends of the scales, indicating that the sample were a relatively high-functioning group of individuals.

Univariate correlations between many of the outcomes and explanatory variables were significant, but not strong. Similarly, simple linear regression revealed a number of significant associations between the SF-36 Summary Scores and the performance measures, but none of them were able to explain more than 24% of the variance associated with the quality of life scales. In order to explain further variation, and to determine the effects of groups of performance measures, multiple linear regression analysis was conducted. Specific models were developed for men and women. Physical health of men was best predicted by the hemiplegic hand Box and Block Test. The OARS IADL Index and the Chedoke-McMaster Stroke Assessment Scale, Impairment Inventory, best predicted mental health of women. Women's physical health status was less well predicted, but was a significant model. It included the Chedoke-McMaster Stroke Assessment Scale, Impairment Inventory and age. The mental health status of men could not be well-predicted using exclusively non-self-reported measures.

The inclusion of more sensitive impairment and disability performance measures with the Barthel Index of ADL explained significant amounts of variation in the physical and mental health components of quality of life. Thus, it may be important for rehabilitation professionals to set goals that go beyond independence in basic activities.

The models developed in this study contain only performance-based measures, and they are able to explain the mental and physical health components of quality of life relatively accurately. It is feasible, then, to consider using performance-based measures to explain quality of life in those individuals who are unable to complete quality of life questionnaires or interviews.

This study was successful in completing its objective to determine which performance-based measures correlate highly with quality of life one year post-stroke. The relationships between health-related quality of life and physical impairment and disability have been further clarified, and predictive models have been suggested to allow estimation of health-related quality of life in non-communicative individuals. Future studies should be conducted to test these models, and to attempt to replicate the associations determined in this study. Furthermore, ambitious intervention studies which attempt to improve the performance of tasks by stroke patients should be undertaken. Our ultimate goal in researching the quality of life of stroke patients is to discover ways to improve their health and lives. While our understanding of the health-related quality of life of stroke patients is improving, our methods of altering it are lagging behind.

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APPENDIX A

French and English Letters to Potential Participants and Consent Forms

«date»
Chèr(e) «nom»,

Des chercheurs de l'Hôpital Général de Montréal et de l'Université McGill effectuent actuellement une recherche qui a pour but de déterminer la relation entre les capacités d'une personne à accomplir des tâches physiques et sa qualité de vie après un accident cérébrovasculaire. Étant donné que vous étiez un(e) patient(e) de l'Hôpital Général de Montréal pendant les douze derniers mois, nous vous demandons de participer à notre étude.

Si vous acceptez d'y participer, nous vous demanderons de répondre à une entrevue téléphonique et une évaluation à votre domicile de votre état de santé. Cette entrevue et cette évaluation se feront au moment qui vous conviendra le mieux. L'entrevue téléphonique comporte des questions sur l'impact qu'aurait votre santé sur votre qualité de vie ainsi que des questions sur votre capacité de memorisation, votre autonomie pour les tâches ménagères et soins corporels, votre réseau de soutien social et votre capacité de vous déplacer dans votre quartier pour vos courses. L'entrevue téléphonique prendra environ trente à quarante minutes de votre temps. Une ou deux journées après l'entrevue téléphonique, une physiothérapeute (Mme Sara McEwen) se rendra à votre domicile pour observer votre capacité à la marche, l'usage de vos mains et la façon de percevoir votre entourage visuellement. La physiothérapeute évaluera aussi vos capacités d'accomplir vos tâches ménagères et vos soins corporels, c'est à dire manger, faire votre toilette et le mouvement volontaire de vos bras et vos jambes. L'évaluation à votre domicile ne durera pas plus qu'une heure et quart.

Votre nom et votre entretien resteront strictement confidentiels. Ceci signifie que votre nom n'apparaîtra jamais dans des publications ou présentations quelconques portant sur les résultats de cette recherche.

Nous désirons également souligner que votre participation à cette étude ne vous bénéficiera pas directement mais vous aurez contribué à une meilleure connaissance de la qualité de vie des patients ayant subi un accident cérébrovasculaire. Nous aimerions obtenir votre participation à cette étude. Toutefois, cette participation est totalement volontaire.

Dans une semaine, une de nos représantantes vous téléphonera pour vous expliquer l'étude et pour répondre à vos questions. En même temps, nous vous demanderons si vous voulez participer. Si vous êtes interessé(e) à participer, vous trouverez, ci-inclu, un formulaire que vous devrez lire et remplir.

Pour obtenir de plus amples renseignements concernant cette étude, veuillez téléphoner à Dr. Nancy Mayo, Mme Claudette Corrigan ou Mme Sara McEwen au 398-3245. Si vous ne voulez pas que nous vous téléphonions, veuillez contacter Lisa Wadup au bureau du Docteur Côté (937-6011, poste 4728).

Nous vous remercions pour l'attention que vous porterez à notre demande.

Robert Côté, M.D.
Service de neurologie
Hôpital Général de Montréal
1650 avenue Cedar
Montréal Québec
H3G 1A4

PROJET: PERFORMANCE-BASED CORRELATES OF HEALTH-RELATED QUALITY OF LIFE IN COMMUNITY DWELLING PERSONS WITH STROKE

FORMULAIRE DE CONSENTEMENT

J'ai lu la lettre du Docteur Robert Côté, ou quelqu'un me l'a lue et je comprends ce qu'on me demande.

Je consens à l'entrevue téléphonique ainsi qu'à l'évaluation à mon domicile par une physiotherapeute (Mme Sara McEwen).

Je comprends que mon nom et tout autre renseignement resteront confidentiels.

Je comprends que ce projet ne m'apportera peut-être aucun avantage personnel mais j'aurai contribué(e) à une meilleure connaissance de la qualité de vie des patients ayant subi un accident cérébrovasculaire.

Je comprends que ma participation est totalement volontaire et je peux retirer ma candidature du projet sans que cette décision n'entraîne aucune conséquence.

Ma signature apposée ci-dessous indique que j'ai lu ce formulaire, ou que quelqu'un me l'a lu et je consens à participer à l'étude.

______________________________________ ____________

Signature du participant/de la participante **Date**

______________________________________ ____________

Signature du témoin **Date**

Dear <name>,

Researchers at the Montreal General Hospital and McGill University are conducting a study to determine the relationship between a person's ability to perform certain physical tasks and his or her quality of life after a stroke. As you were hospitalized at the Montreal General Hospital during the past year, we are asking you to participate in this study.

If you decide to participate, you will be required to complete a pre-scheduled telephone interview and home assessment. During the telephone interview you will be asked questions about the impact of your health on your quality of life, as well as questions about your thinking and memory ability, your self-care abilities, your social support network, and your ability to carry out activities in the community such as shopping. Thirty to forty minutes of your time will be required. One or two days later, a physiotherapist (Ms. Sara McEwen) will visit you at home to observe your ability to walk, use your hands and visually perceive your environment. Your ability to perform self-care activities such as eating and grooming will also be assessed. As well, the physiotherapist will assess the voluntary movement of your arms and legs. The session should not take longer than one hour and fifteen minutes.

Your name and all other information will be kept confidential. This means that your name will never be identified in any publications or presentations of the findings of this research.

There are no personal benefits to you in participating. However, you will have contributed to a better knowledge of the quality of life in stroke patients. Your participation would be greatly appreciated. However, your participation is strictly voluntary.

Within the next week, a study representative will contact you by telephone to further explain the study and to answer any questions you might have. At that time, you will be asked if you would consider participating. If you are interested, please read and sign the enclosed consent form.

If you have any further questions about this study, please do not hesitate to call Dr. Nancy Mayo, Mme Claudette Corrigan, or Ms. Sara McEwen at 398-3245. If you do not wish to be contacted at home, please inform Lisa Wadup at Dr. Côté's office (937-6011 ext 4728).

Thank you for taking the time to consider our request.

Dr. Robert Côté, MD
Department of Neurology
Montreal General Hospital
1650 Cedar Ave.
Montréal, Québec
H3G 1A4

STUDY: PERFORMANCE-BASED CORRELATES OF HEALTH-RELATED QUALITY OF LIFE IN COMMUNITY DWELLING PERSONS WITH STROKE

CONSENT FORM

I have read the letter from Dr. Robert Côté, or have had it read to me, and I understand what is being asked.

I agree to be interviewed over the telephone and have a physiotherapist (Ms. Sara McEwen) assess me at home.

I understand that my name and all other information will be kept confidential.

I understand that there are no personal benefits to me, however I will have contributed to a better knowledge of quality of life in stroke patients.

I understand that my participation is completely voluntary, and that I may stop participating at any time without affecting my current medical care.

My signature below signifies that I have read this form, or have had it read to me. I understand what is being asked of me and I agree to participate in this study.

Signature of participant Date

Signature of witness Date

APPENDIX B

Instruments

Subject demographic and health information
Home assessment form
Geriatric Depression Scale (French and English)
OARS IADL (French and English)
Chedoke-McMaster Stroke Assessment Scale, Impairment Inventory
Timed Up and Go
Box and Block Test
Albert's Test
SF-36 Health Status Survey (French and English)

PERFORMANCE-BASED CORRELATES OF HEALTH-RELATED QUALITY OF LIFE IN COMMUNITY DWELLING INDIVIDUALS WITH STROKE

SUBJECT DEMOGRAPHIC AND HEALTH INFORMATION

PATIENT INFORMATION

Subject number_____ Chart number_____ Sex_____ Language_____
Date of birth__/__/__ Age_____ Date of Stroke__/__/__
Phone number__________ Address____

____
____
____

Name/address/phone number ____
(next of kin)____
____
Date of Discharge__/__/__ Place of Discharge____

Nature of Stroke
Side: Right/Left/Bilateral/Unclear
Type of stroke____
Area of lesion____

CHARLSON COMORBIDITY INDEX

Condition	**Assigned Weight**	**Value**
Myocardial Infarct	1	______
Congestive Heart Failure		______
Peripheral Vascular Disease		______
Cerebrovascular Disease		______
Dementia		______
Chronic Pulmonary Disease		______
Connective Tissue Disease		______
Ulcer Disease		______
Mild Liver Disease		______
Diabetes		______
Hemiplegia	2	______
Moderate or Severe Renal Disease		______
Diabetes with end organ damage		______
Any Tumor		______
Leukemia		______
Lymphoma		______
Moderate or Severe Liver Disease	3	______
AIDS	6	______
Metastatic Solid Tumor		______
TOTAL		______

Comments____
____
____
____

PERFORMANCE-BASED CORRELATES OF HEALTH-RELATED QUALITY OF LIFE IN COMMUNITY DWELLING PERSONS WITH STROKE

HOME ASSESSMENT FORM

Subject number______

CHEDOKE-MCMASTER STROKE ASSESSMENT SCALE, IMPAIRMENT INVENTORY

Test Item	Stage
Postural Control	______
Arm	______
Hand	______
Leg	______
Foot	______
TOTAL	______/42

Comments____

____

TIMED UP AND GO

"Rise from the chair, walk to the line on the floor, turn, return to the chair and sit down again."

Time______ Comments ____

____

BOX AND BLOCK TEST

Hemiplegic Hand (right/left) _______ Non-hemiplegic Hand ______

Comments ____

____

ALBERT'S TEST

Score______ Comments____

____

GERIATRIC DEPRESSION SCALE

Score _______ Comments _______________________________________

____

GDS

Please circle yes or no for each question.

1. Are you basically satisfied with your life? **YES / NO**
2. Have you dropped many of your activities and interests? **YES / NO**
3. Do you feel that your life is empty? **YES / NO**
4. Do you often get bored? **YES / NO**
5. Are you hopeful about the future? **YES / NO**
6. Are you bothered by thoughts you can't get out of your head? **YES / NO**
7. Are you in good spirits most of the time? **YES / NO**
8. Are you afraid that something bad is going to happen to you? **YES / NO**
9. Do you feel happy most of the time? **YES / NO**
10. Do you often feel helpless? **YES / NO**
11. Do you often get restless and fidgety? **YES / NO**
12. Do you prefer to stay at home, rather than going out and doing new things? **YES / NO**
13. Do you frequently worry about the future? **YES / NO**
14. Do you feel that you have more problems with memory than most? **YES / NO**
15. Do you think it is wonderful to be alive now? **YES / NO**
16. Do you often feel downhearted and blue? **YES / NO**
17. Do you feel pretty worthless the way you are now? **YES / NO**
18. Do you worry a lot about the past? **YES / NO**
19. Do you find life very exciting? **YES / NO**
20. Is it hard for you to get started on new projects? **YES / NO**
21. Do you feel full of energy? **YES / NO**
22. Do you feel that your situation is hopeless? **YES / NO**
23. Do you think that most people are better off than you are? **YES / NO**
24. Do you frequently get upset over little things? **YES / NO**
25. Do you frequently feel like crying? **YES / NO**
26. Do you have trouble concentrating? **YES / NO**
27. Do you enjoy getting up in the morning? **YES / NO**
28. Do you prefer to avoid social gatherings? **YES / NO**
29. Is it easy for you to make decisions? **YES / NO**
30. Is your mind as clear as it used to be? **YES / NO**

GDS - GERIATRIC DEPRESSION SCALE

Veuillez encercler oui ou non pour chaque question.

1. Fondamentalement, êtes-vous satisfait (e) de votre vie? oui/non
2. Avez-vous abandonné plusieurs de vos activités et intérêts? oui/non
3. Sentez-vous que votre vie est vide? oui/non
4. Vous ennuyez-vous souvent? oui/non
5. Avez-vous confiance en ce qui concerne l'avenir? oui/non
6. Êtes-vous dérangé (e) par des pensées que vous ne parvenez pas à vous sortir de la tête? oui/non
7. Êtes-vous généralement de bonne humeur? oui/non
8. Craignez-vous qu'il vous arrive quelque chose de mauvais ? oui/non
9. Vous sentez-vous heureux (se) la plupart du temps? oui/non
10. Vous sentez-vous souvent démuni(e)? oui/non
11. Etes-vous souvent agité (e) et nerveux (nerveuse)? oui/non
12. Préférez-vous rester chez vous le soir plutôt que de sortir et essayer quelque chose de nouveau? oui/non
13. Vous inquiétez-vous souvent de l'avenir? oui/non
14. Pensez-vous que vous-avez plus de problèmes de mémoire que ceux de la majorité des gens? oui/non
15. Pensez-vous que c'est merveilleux d'être en vie maintenant? oui/non
16. Êtes-vous souvent abattu (e) et découragé (e)? oui/non
17. Dans votre état actuel, vous sentez-vous bon (bonne) à rien? oui/non
18. Vous inquiétez-vous souvent du passé? oui/non
19. Trouvez-vous que la vie est excitante? oui/non
20. Avez-vous du mal à vous lancer dans de nouveaux projets? oui/non
21. Vous sentez-vous pleine d'énergie? oui/non
22. Vous sentez-vous que votre situation est désespérée? oui/non
23. Pensez-vous que la plupart des gens sont en meilleure position que vous? oui/non
24. Les petites choses vous bouleversent-elles? oui/non
25. Avez-vous souvent envie de pleurer? oui/non
26. Avez-vous des problèmes de concentration? oui/non
27. Êtes-vous heureux (heureuse) de vous lever le matin? oui/non
28. Préferez-vous éviter les réunions sociales? oui/non
29. Prenez-vous facilement des décisions? oui/non
30. Êtes-vous aussi lucide qu'autrefois? oui/non

OARS - IADL/ADL SCALE

Je désire maintenant vous poser quelques questions concernant vos occupations et activités routinières dans le cadre de votre vie quotidienne. Je désire savoir si vous pouvez accomplir ces tâches sans aide, si vous avez besoin d'une certaine aide ou si vous êtes incapable de vous en tirer seul (e).

(LORSQU'ELLES SONT APPLICABLES À LA PERSONNE INTERROGÉE, VEUILLEZ LIRE TOUTES LES RÉPONSES INDIQUÉES POUR LES QUESTIONS 56 À 69,)

Échelle IADL

1. Êtes-vous en mesure d'utiliser le téléphone...
   2. sans aide, y compris chercher les numéros et composer;
   1. avec une certaine aide (vous pouvez répondre et composer le numéro de la téléphoniste en cas d'urgence, mais vous avez besoin d'un téléphone spécial ou d'aide pour chercher un numéro et composer);
   0. vous êtes incapable d'utiliser le téléphone.
   - pas de réponse

2. Êtes-vous en mesure de vous rendre à des lieux où vous ne pouvez pas aller à pied...
   2. sans aide (vous prenez l'autobus, un taxi ou conduisez votre propre voiture);
   1. avec une certaine aide (il faut que quelqu'un vous aide ou vous accompagne lorsque vous vous déplacez);
   0. vous êtes incapable de vous déplacer sans avoir recours à des dispositions spéciales, par exemple un véhicule d'urgence telle qu'une ambulance.
   - pas de réponse

3. Êtes-vous en mesure d'acheter vos provisions ou des vêtements (DANS LA MESURE OÙ LA PERSONNE INTERROGÉE A ACCÈS À UN MODE DE TRANSPORT)...
   2. sans aide (vous faites vous-même tout le nécessaire dans la mesure où vous avez accès à un mode de transport);
   1. vous avez besoin d'aide (quelqu'un doit vous accompagner lorsque vous faites vos achats);
   0. vous êtes incapable de faire vos achats.
   - pas de réponse

4. Êtes-vous en mesure de préparer vos propres repas...
   2. sans aide (vous planifiez et préparez la totalité de vos repas);
   1. avec une certaine aide (vous êtes en mesure de préparer certaines choses mais ne pouvez préparer la totalité de vos repas);
   0. vous êtes incapable de préparer quoi que ce soit.
   - pas de réponse

5. Êtes-vous en mesure de faire votre ménage...
   2. sans aide (vous lavez le plancher et autres);
   1. avec une certaine aide (vous pouvez faire certains travaux faciles mais ne pouvez faire les gros travaux);
   0. vous êtes incapable de vous occuper des travaux ménagers.
   \- pas de réponse.

6. Êtes-vous en mesure de prendre vos propres médicaments...
   2. sans aide (doses correctes, heures correctes);
   1. avec une certaine aide (vous pouvez prendre vos propres médicaments si quelqu'un vous les prépare et vous dit quand les prendre);
   0. vous êtes incapable de prendre vos propres médicaments.
   \- pas de réponse.

7. Êtes-vous en mesure de vous occuper de vos finances...
   2. sans aide (vous faites vos chèques et réglez vos comptes;
   1. avec une certaine aide (vous vous tirez de vos achats quotidiens, mais avez besoin d'aide pour gérer votre carnet de chèques et régler vos factures);
   0. vous êtes incapable de vous occuper de vos finances.
   \- pas de réponse.

OARS -Activities of Daily Living

Now I'd like to ask you about some of the activities of daily living, things that we all need to do as a part of our daily lives. I would like to know if you can do these activities without any help at all, or if you need some help to do them, or if you can't do them at all.

(Be sure to read all answer choices if applicable in questions 1. through 15. to respondent.)

Instrumental ADL

1. Can you use the telephone...
   - 2 without help, including looking up numbers and dialing
   - 1 with some help (can answer the phone or dial operator in an emergency, but need a special phone or help in getting the number, or dialing)
   - 0 or are you completely unable to use the telephone?
   - not answered.

2. Can you get to places out of walking distance...
   - 2 without help (can travel on buses, taxis, or drive your own car).
   - 1 with some help (need someone to help you or go with you when travelling) or
   - 0 you are unable to travel unless emergency arrangements are made for a specialized vehicle like an ambulance?
   - not answered.

3. Can you go shopping for groceries or clothes (assuming has transportation)...
   - 2 without help (taking care of all shopping needs yourself assuming you had transportation)
   - 1 with some help (need someone to go with you on all shopping trips),
   - 0 or are you completely unable to do any shopping?
   - not answered

4. Can you prepare your own meals...
   - 2 without help (plan and cook full meals yourself),
   - 1 with some help (can prepare some things but unable to cook full meals yourself)
   - 0 or are you completely unable to prepare any meals?
   - not answered

5. Can you do your own housework...
   - 2 without help (can scrub floors, etc.)
   - 1 with some help (can do light housework but need help with heavy work),
   - 0 or are you completely unable to do any housework?
   - not answered

6. Can you take your own medicine...
   - 2 without help (in the right doses at the right time),
   - 1 with some help (able to take medicine if someone prepares it for you and/or reminds you to take it),
   - 0 or are you completely unable to take your own medicines?
   - not answered

7. Can you handle your own money...
   - 2 without help (write checks, pay bills, etc.),
   - 1 with some help (manage day to day buying but need help with managing chequebook and paying bills),
   - 0 or are you completely unable to handle your own money
   - not answered

CHEDOKE- McMASTER STROKE ASSESSMENT
SCORE FORM Page 1 of 4
IMPAIRMENT INVENTORY: SHOULDER PAIN AND POSTURAL CONTROL

Start at Stage 4. Starting position: indicated on the side and by underlining. No support is permitted.
Stage the patient at the highest stage where he achieves at least two "X"s.

		SHOULDER PAIN			POSTURAL CONTROL
1	☐	constant, severe pain in the upper extremity with painful pathology in more than just the shoulder.		☐	not yet Stage 2
2	☐	intermittent, severe pain in the upper extremity with painful pathology in more than just the shoulder	Supine	☐	facilitated log roll to side lying
			Side lying	☐	resistance to trunk rotation
			Sit	☐	static righting with facilitation
3	☐	constant pain in the upper extremity with pathology in just the shoulder	Supine	☐	log roll to side lying
			Sit	☐	move forward and backward
			Stand	☐	remain upright 5 sec.
4	☐	intermittent pain in the upper extremity with pathology in just the shoulder	Supine	☐	segmental rolling to side lying
			Sit	☐	static righting
			Sit	☐	stand
5	☐	shoulder pain is noted during testing, but the functional activities that the patient normally performs are not affected by the pain	Sit	☐	dynamic righting side to side, feet on floor
			Sit	☐	to stand with equal weight bearing
			Stand	☐	step forward onto weak foot, transfer weight
6	☐	no shoulder pain, but at least one prognostic indicator is present • Arm Stage 1 or 2 • Scapula elevated/depressed • Loss of range • Flex/Abd < 90° • Ext Rotn < 60°	Sit	☐	dynamic righting backwards and sideways with displacement, feet off floor
			Stand	☐	on weak leg, 5 seconds ☐ sec.
			Stand	☐	sideways braiding
7	☐	shoulder pain and prognostic indicators are absent	Stand	☐	on weak leg: abduction of strong leg
			Stand	☐	tandem walking 2 m in 5 sec
			Stand	☐	walk on toes 2 m

☐ STAGE OF SHOULDER PAIN

☐ STAGE OF POSTURAL CONTROL

COPY FREELY - DO NOT CHANGE

CHEDOKE-McMASTER STROKE ASSESSMENT
SCORE FORM Page 2 of 4
IMPAIRMENT INVENTORY: STAGE OF RECOVERY OF ARM AND HAND

Start at Stage 3. Starting position: sitting with forearm in lap in a neutral position, wrist at 0° and fingers slightly flexed. Changes from this position are indicated by underlining. Stage the patient at the highest stage where he achieves at least two "X's".

	ARM	HAND
1	☐ not yet Stage 2	☐ not yet Stage 2
2	☐ resistance to passive shoulder abduction or elbow extension	☐ positive Hoffman
	☐ facilitated elbow extension	☐ resistance to passive wrist or finger extension
	☐ facilitated elbow flexion	☐ facilitated finger flexion
3	☐ touch opposite knee	☐ wrist extension > ½ range
	☐ touch chin	☐ finger/wrist flexion > ½ range
	☐ shoulder shrugging > ½ range	☐ <u>supination, thumb in extension</u>: thumb to index finger
4	☐ extension synergy, then flexion synergy	☐ finger extension, then flexion
	☐ shoulder flexion to 90°	☐ thumb extension > ½ range, then lateral prehension
	☐ <u>elbow at side, 90° flexion</u>: supination, then pronation	☐ finger flexion with lateral prehension
5	☐ flexion synergy, then extension synergy	☐ finger flexion, then extension
	☐ shoulder abduction to 90° with pronation	☐ <u>pronation</u>: finger abduction
	☐ <u>shoulder flexion to 90°</u>: pronation then supination	☐ opposition of little finger to thumb
6	☐ hand from knee to forehead 5 x in 5 sec.	☐ <u>pronation</u>: tap index finger 10 x in 5 sec
	☐ <u>shoulder flexion to 90°</u>: trace a figure 8	☐ <u>pistol grip</u>: pull trigger, then return
	☐ raise arm overhead with full supination	☐ wrist and finger extension with finger abduction
7	☐ clap hands overhead, then behind back 3 x in 5 sec	☐ thumb to finger tips, then reverse 3 x in 12 sec
	☐ <u>shoulder flexion to 90°</u>: scissor in front 3 x in 5 sec	☐ bounce a ball 4 times in succession, then catch
	☐ <u>elbow at side, 90° flexion</u>: resisted shoulder external rotation	☐ pour 250 ml. from 1 litre pitcher, then reverse

☐ **STAGE OF ARM**

☐ **STAGE OF HAND**

COPY FREELY - DO NOT CHANGE .

CHEDOKE-McMASTER STROKE ASSESSMENT
SCORE FORM **Page 3 of 4**
IMPAIRMENT INVENTORY: STAGE OF RECOVERY OF LEG AND FOOT

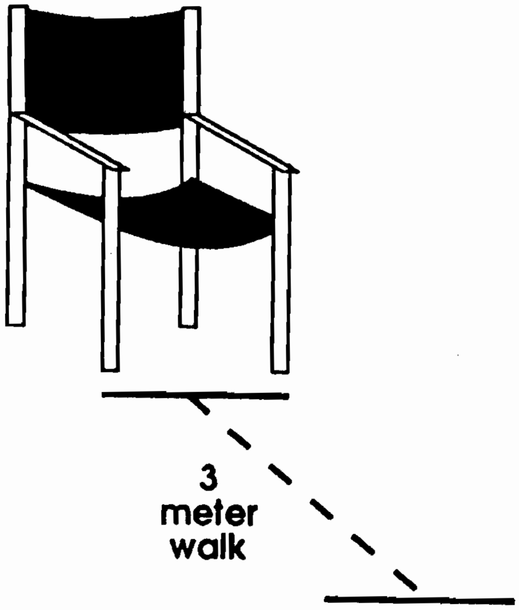
LEG: Start at Stage 4 with the patient in crook lying. FOOT: Start at Stage 3 with the patient in supine. Test position is beside the item or underlined. If not indicated, the position has not changed. Score the highest stage in which the patient achieves at least two "Xs". For "standing" test items, light support may be provided but weight bearing through the hand is not allowed. Shoes and socks off.

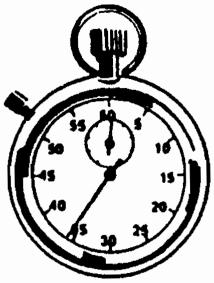
		LEG		FOOT
1		☐ not yet Stage 2		☐ not yet Stage 2
2	Crook lying	☐ resistance to passive hip or knee flexion	Crook lying	☐ resistance to passive dorsiflexion
		☐ facilitated flexion		☐ facilitated dorsiflexion or toe extension
		☐ facilitated extension		☐ facilitated plantarflexion
3		☐ abduction: adduction to neutral	Supine	☐ plantarflexion > ½ range
		☐ hip flexion to 90°	Sit	☐ some dorsiflexion
		☐ full extension		☐ extension of toes
4		☐ hip flexion to 90° then extension synergy		☐ some eversion
	Sit	☐ bridging hip with equal weightbearing		☐ inversion
		☐ knee flexion beyond 100°		☐ legs crossed: dorsiflexion, then plantarflexion
5	Crook lying	☐ extension synergy, then flexion synergy		☐ legs crossed: toe extension with ankle plantarflexion
	Sit	☐ raise thigh off bed		☐ sitting with knee extended: ankle plantarflexion, then dorsiflexion
	Stand	☐ hip extension with knee flexion 5	Stand	☐ heel on floor: eversion
6	Sit	☐ lift foot off floor 5 x in 5 sec.		☐ heel on floor: tap foot 5 x in 5 sec
	Stand	☐ full range internal rotation		☐ foot circumduction
		☐ trace a pattern: forward, side, back, return		☐ knee straight, heel off floor: eversion
7	Stand	☐ unsupported: rapid high stepping 10 x in 5 sec		☐ heel touching forward, then toe touching behind, repeat 5 x in 10 sec
		☐ trace a pattern quickly; forward, side, back, reverse		☐ circumduction quickly, reverse
		☐ on weak leg with support: hop on weak leg		☐ up on toes, then back on heels 5 x
		☐ STAGE OF LEG		☐ STAGE OF FOOT

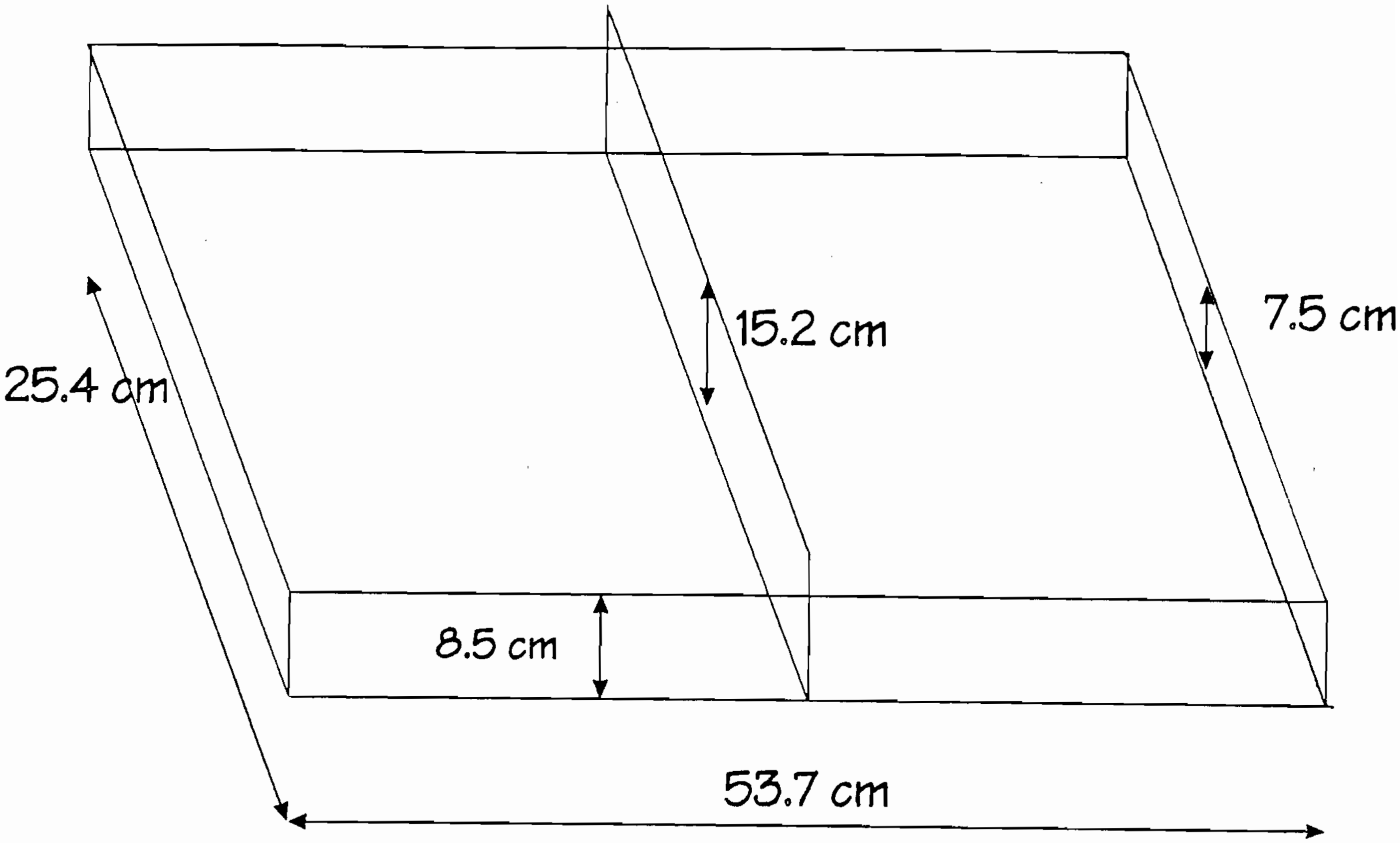
COPY FREELY - DO NOT CHANGE

Timed Up and Go

The subject is given the following instructions:
"Rise from the chair, walk to the line on the floor, turn, return to the chair and sit down again."





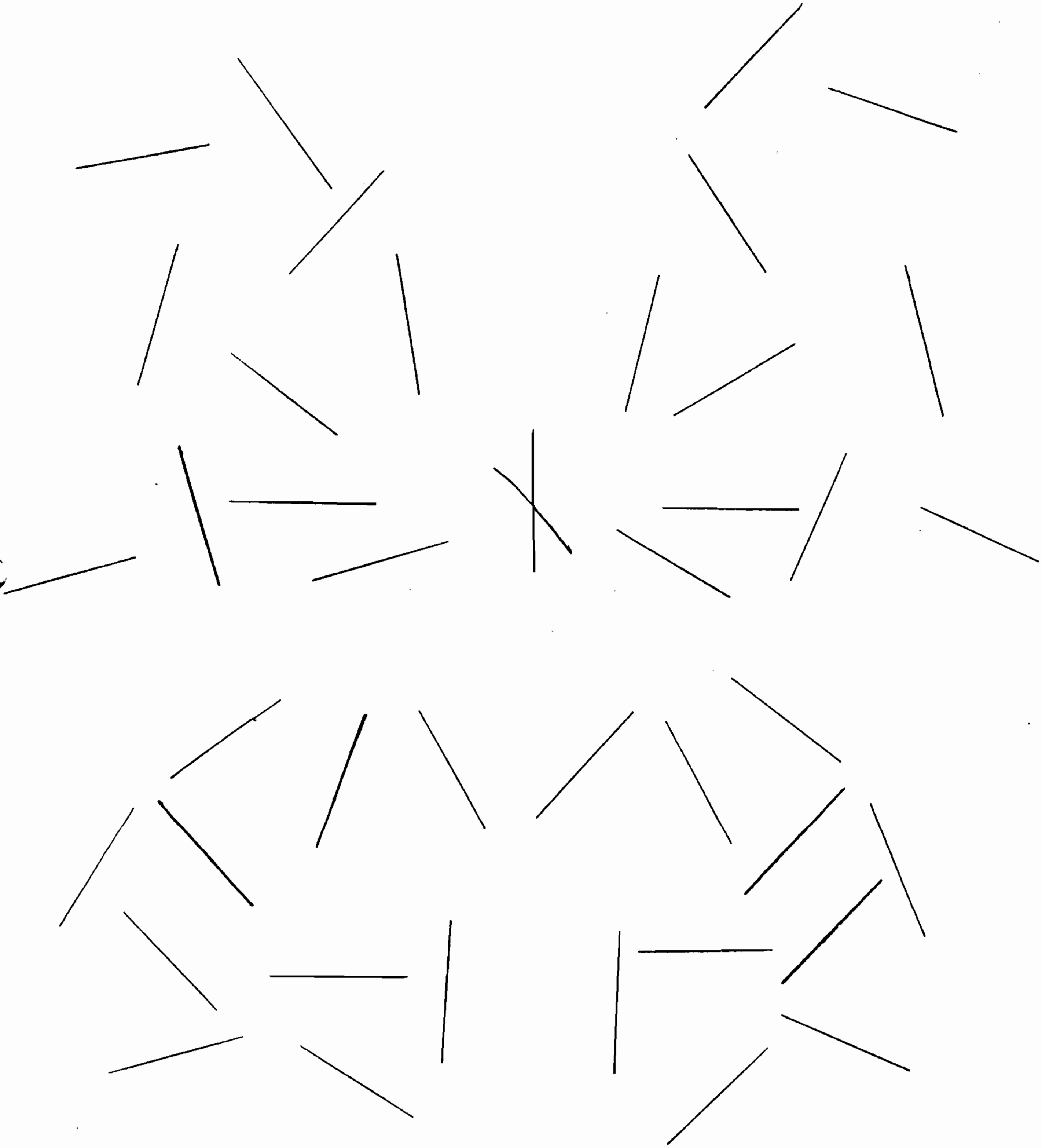


The Box and Block Test
Box Dimensions
(constructed of 1 cm thick plywood)

The Box and Block Test involves moving as many one inch blocks as possible from one side of the box to the other in a 60 second period. The subjects are permitted a 15 second trial period. The box is positioned lengthwise along the edge of a standard height table, with the subject facing the box in a standard height chair. The trials will be done according to procedures described by Mathiowetz et al., 1985.

The Box and Block Test was copyrighted in 1957 by Holser Buehler and Fuchs, in Cromwell's <u>Occupational Therapist's Manual for Basic Skill Assessment; Primary Prevocational Education</u>.

Albert's Test



The middle line is crossed out as an example. The patient is instructed to cross out all of the remaining lines on the page.

SF-36 HEALTH STATUS SURVEY/CANADA

INSTRUCTIONS: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

(circle one)

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

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

(circle one)

Much better now than one year ago	1
Somewhat better now than one year ago	2
About the same as one year ago	3
Somewhat worse now than one year ago	4
Much worse now than one year ago	5

1 ☐ ☐ ☐ HOSPITAL UNIT ______________________

3. The following items are about activities you might do during a typical day. Does <u>your health now limit you</u> in these activities? If so, how much?

(circle one number on each line)

	ACTIVITIES	Yes, Limited A Lot	Yes, limited A Little	No, Not Limited At All
a.	**Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b.	**Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c.	Lifting or carrying groceries	1	2	3
d.	Climbing **several** flights of stairs	1	2	3
e.	Climbing **one** flight of stairs	1	2	3
f.	Bending, kneeling, or stooping	1	2	3
g.	Walking **more than a kilometre**	1	2	3
h.	Walking **several blocks**	1	2	3
i.	Walking **one block**	1	2	3
j.	Bathing or dressing yourself	1	2	3

4. During the <u>past 4 weeks</u> have you had any of the following problems with your work or other regular daily activities <u>as a result of your physical health</u>?

(circle one number on each line)

		YES	NO
a.	Cut down the **amount of time** you spent on work or other activities	1	2
b.	**Accomplished less** than you would like	1	2
c.	Were limited in the **kind** of work or other activities	1	2
d.	Had **difficulty** performing the work or other activities (for example, it took extra effort)	1	2

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(circle one number on each line)

		YES	NO
a.	Cut down the **amount of time** you spent on work or other activities	1	2
b.	**Accomplished less** than you would like	1	2
c.	Didn't do work or other activities as **carefully** as usual	1	2

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

(circle one)

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

7. How much bodily pain have you had during the past 4 weeks?

(circle one)

None	1
Very mild	2
Mild	3
Moderate	4
Severe	5
Very severe	6

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

(circle one)

Not at all	1
A little bit	2
Moderately	3
Quite a bit	4
Extremely	5

the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks

(circle one number on each line)

	All of the Time	Most of the time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Did you feel full of pep?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and blue?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

10. 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)

All of the time 1

Most of the time 2

Some of the time 3

A little of the time 4

None of the time 5

11. How **TRUE** or **FALSE** is each of the following statements for you?

(circle one number on each line)

		Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a.	I seem to get sick a little easier than other people	1	2	3	4	5
b.	I am as healthy as anybody I know	1	2	3	4	5
c.	I expect my health to get worse	1	2	3	4	5
d.	My health is excellent	1	2	3	4	5

QUESTIONNAIRE SUR L'ÉTAT DE SANTÉ SF-36

DIRECTIVES: Les questions qui suivent portent sur votre santé, telle que vous la percevez. Vos réponses permettront de suivre l'évolution de votre état de santé et de savoir dans quelle mesure vous pouvez accomplir vos activités courantes.

Répondez à toutes les questions en suivant les indications qui vous sont données. En cas de doute, répondez de votre mieux.

1. En général, diriez-vous que votre santé est:

(encerclez une seule réponse)

Excellente	1
Très bonne	2
Bonne	3
Passable	4
Mauvaise	5

2. <u>Par comparaison à l'an dernier</u>, comment évaluez-vous, maintenant, votre santé générale?

(encerclez une seule réponse)

Bien meilleure maintenant que l'an dernier	1
Un peu meilleure maintenant que l'an dernier	2
À peu près la même que l'an dernier	3
Un peu moins bonne maintenant que l'an dernier	4
Bien moins bonne maintenant que l'an dernier	5

☐2 ☐ ☐ ☐ Service d'hôpital________________________________

(IQOLA SF-36 French (Canada) Version 1.2)

3. Les questions suivantes portent sur les activités que vous pourriez avoir à faire au cours d'une journée normale. Votre état de santé actuel vous limite-t-il dans ces activités? Si oui, dans quelle mesure?

(encerclez un seul chiffre par ligne)

ACTIVITÉS	Mon état de santé me limite beaucoup	Mon état de santé me limite un peu	Mon état de santé ne me limite pas du tout
a. Dans les activités exigeant un effort physique important comme courir, soulever des objets lourds, pratiquer des sports violents	1	2	3
b. Dans les activités modérées comme déplacer une table, passer l'aspirateur, jouer aux quilles ou au golf	1	2	3
c. Pour soulever ou transporter des sacs d'épicerie	1	2	3
d. Pour monter plusieurs étages à pied	1	2	3
e. Pour monter un seul étage à pied	1	2	3
f. Pour me pencher, me mettre à genoux ou m'accroupir	1	2	3
g. Pour faire plus d'un kilomètre à pied	1	2	3
h. Pour faire plusieurs coins de rue à pied	1	2	3
i. Pour marcher d'un coin de rue à l'autre	1	2	3
j. Pour prendre un bain ou m'habiller	1	2	3

4. Au cours des quatre dernières semaines, avez-vous eu l'une ou l'autre des difficultés suivantes au travail ou dans vos autres activités quotidiennes à cause de votre état de santé physique?

(encerclez un seul chiffre par ligne)

	OUI	NON
a. Avez-vous dû consacrer **moins de temps** à votre travail ou à d'autres activités?	1	2
b. **Avez-vous accompli moins** de choses que vous l'auriez voulu?	1	2
c. Avez-vous été limité(e) dans la **nature** de vos tâches ou de vos autres activités?	1	2
d. Avez-vous eu **du mal** à accomplir votre travail ou vos autres activités (par exemple vous a-t-il fallu fournir un effort supplémentaire)?	1	2

5. Au cours des quatre dernières semaines, avez-vous eu l'une ou l'autre des difficultés suivantes au travail ou dans vos autres activités quotidiennes à cause de l'état de votre moral (comme le fait de vous sentir déprimé(e) ou anxieux(se))?

(encerclez un seul chiffre par ligne)

	OUI	NON
a. Avez-vous dû consacrer **moins de temps** à votre travail ou à d'autres activités?	1	2
b. Avez-vous **accompli moins** de choses que vous l'auriez voulu?	1	2
c. Avez-vous fait votre travail ou vos autres activités avec **moins de soin** qu'à l'habitude?	1	2

6. Au cours des quatre dernières semains, dans quelle mesure votre état physiques ou moral a-t-il nui à vos activités sociales habituelles (famille, amis, voisins ou autres groupes)?

(encerclez une seule réponse)

Pas du tout	1
Un peu	2
Moyennement	3
Beaucoup	4
Enormément	5

7. Au cours des quatre dernières semaines, avez-vous éprouvé des douleurs physiques?

(encerclez une seule réponse)

Aucune douleur	1
Douleurs très légères	2
Douleurs légères	3
Douleurs moyennes	4
Douleurs intenses	5
Douleurs très intenses	6

(IQOLA SF-36 French (Canada) Version 1.2)

8. Au cours des quatre dernières semaines, dans quelle mesure la douleur a-t-elle nui à vos activités habituelles (au travail comme à la maison)?

(encerclez une seule réponse)

Pas du tout	1
Un peu	2
Moyennement	3
Beaucoup	4
Enormément	5

9. Ces questions portent sur les quatre dernières semaines. Pour chacune des questions suivantes, donnez la réponse qui s'approche le plus de la façon dont vous vous êtes senti(e).

Au cours des quatre dernières semaines, combien de fois:

(encerclez un seul chiffre par ligne)

	Tout le temps	**La plupart du temps**	**Souvent**	**Quel-que-fois**	**Rare-ment**	**Jamais**
a. Vous êtes-vous senti(e) plein(e) d'entrain (de pep)?	1	2	3	4	5	6
b. Avez-vous été très nerveux(se)?	1	2	3	4	5	6
c. Vous êtes-vous senti(e) si déprimé(e) que rien ne pouvait vous remonter le moral?	1	2	3	4	5	6
d. Vous êtes-vous senti(e) calme et serein(e)?	1	2	3	4	5	6
e. Avez-vous eu beaucoup d'énergie?	1	2	3	4	5	6
f. Vous êtes-vous senti(e) triste et abattu(e)?	1	2	3	4	5	6
g. Vous êtes-vous senti(e) épuisé(e) et vidé(e)?	1	2	3	4	5	6
h. Vous êtes-vous senti(e) heureux(se)?	1	2	3	4	5	6
i. Vous êtes-vous senti(e) fatigué(e)?	1	2	3	4	5	6

(IQOLA SF-36 French (Canada) Version 1.2)

10. Au cours des quatre dernières semaines, combien de fois votre état physique ou moral a-t-il nui à vos activités sociales (comme visiter des amis, des parents, etc.)?

(encerclez une seule réponse)

Tout le temps	1
La plupart du temps	2
Parfois	3
Rarement	4
Jamais	5

11. Dans quelle mesure chacun des énoncés suivants est-il VRAI ou FAUX dans votre cas?

(encerclez un seul chiffre par ligne)

	Tout à fait vrai	Plutôt vrai	Ne sais pas	Plutôt faux	Tout à fait faux
a. Il me semble que je tombe malade un peu plus facilement que les autres	1	2	3	4	5
b. Je suis aussi en santé que les gens que je connais	1	2	3	4	5
c. Je m'attends à ce que ma santé se détériore	1	2	3	4	5
d. Ma santé est excellente	1	2	3	4	5

(IQOLA SF-36 French (Canada) Version 1.2)

APPENDIX C

Construction of SF-36 Summary Scales

Construction of the Summary Measures - The Physical Health Summary Score (PCS) and the Mental Health Summary Score.(MCS).

The methods for constructing the PCS and the MCS, along with a computor program to facilitate the process, were provided by the SF-36 Physical and Mental Health Summary Scales: A User's Manual (Ware, 1994).

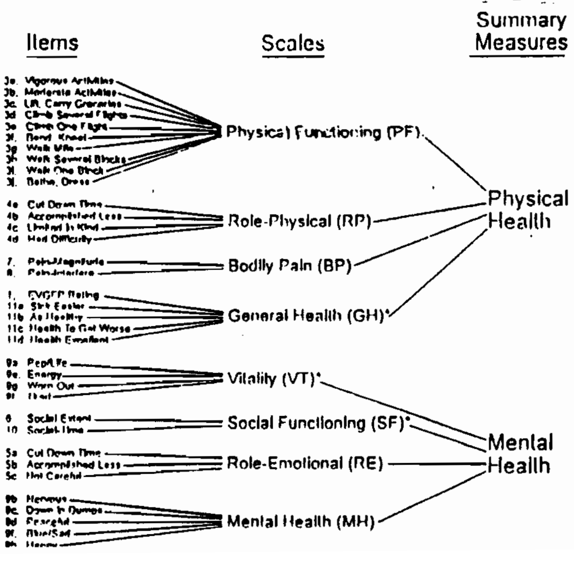
Ware and associates (1994) derived the PCS and MCS using the factor analysis method known as Principal Component Analysis. Figure C1 illustrates the measurement model underlying the SF-36 eight subscales and the two summary scores. Thirty-five of the 36 items are used.

To score the PCS and MCS, three steps are involved:

1. standardization of the eight subscales, using means and standard deviations from the general US population.
2. aggregation of scores using weights (factor score coefficients) from the general US population
3. linear t-score transformation fo the aggregate scores, so that mean is 50 and standard deviation 10 in the general US population.

The advantage of the standardization and norm-based scoring of the PCS and MCS is that results from one can be compared to the other, and their scores have a direct interpretation in relation to the distribution of scores in the general US population.

Figure C1



(From Ware, 1994)

Scoring Steps

1. z-scores are computed by subtracting the US population mean from each SF-36 subscale score and dividing the difference by the corresponding scale standard deviation from the general U.S. population. The formulae are listed below:

   PF_Z=(PF-84.52404) / 22.89490

   RP_Z=(RP-81.19907) / 33.79729

   BP_Z=(BP-75.49196) / 23.55879

   GH_Z=(GH-72.21316) / 20.16964

   VT_Z=(VT-61.05453) / 20.86942

   SF_Z=(SF-83.59753) / 22.37642

   RE_Z=(RE-81.29467) / 33.02717

   MH_Z=(MH-74.84212) /18.01189

2. The scale scores are aggregated by multiplying the z-scores by its respective physical factor score coefficient, and summing the eight products. The formulae are listed below:

   PCS aggregate = (PF_Z*.42402) + (RP_Z*.35119) + (BP_Z*.31754) + (GH_Z*.24954) + (VT_Z*..02877) + (SF_Z*-.00753) + (RE_Z*-.19206) + (MH_Z*-.22069)

   MCS aggregate = (PF_Z*-.22999) + (RP_Z*-.12329) + (BP_Z*-.09731) + (GH_Z*-.01571) + (VT_Z*.23534) + (SF_Z*.26876) + (RE_Z*.43407) + (MH_Z*.48581)

3. Finally, each component score is transformed to the norm-based (50,10) scoring. Each aggregate component scale is mulitplied by 10, and the resulting product is added to 50. Again, the formulae are listed below:

   Transformed PCS = 50 + (PCS aggregate*10)

   Transformed MCS = 50 + (MCS aggregate*10)

APPENDIX D

CORRELATION MATRIX

Pearson Correlation Coefficients for Outcomes, Performance Measures and Selected Confounders

		GH	PF	RP	RE	SF	BP	VT	MH	PCS	MCS	TUG	CMS	S HD
SF-36 Subscales	**General Health (GH)**	1.00												
	Physical Functioning (PF)	**0.50**	1.00											
	Physical Role Limitations (RP)	**0.51**	**0.69**	1.00										
	Emotional Role Limitations (RE)	**0.45**	**0.49**	**0.47**	1.00									
	Social Functioning (SF)	**0.33**	**0.46**	**0.49**	**0.72**	1.00								
	Bodily Pain (BP)	**0.44**	**0.50**	**0.50**	**0.33**	**0.34**	1.00							
	Vitality (VT)	**0.37**	**0.41**	**0.56**	**0.37**	**0.41**	**0.65**	1.00						
	Mental Health (MH)	**0.43**	**0.56**	**0.49**	**0.72**	**0.82**	0.29	**0.53**	1.00					
SF-36 Summary Scales	**Physical Health Summary Score (PCS)**	**0.63**	**0.82**	**0.80**	0.27	0.27	**0.77**	**0.55**	0.29	1.00				
	Mental Health Summary Score (MCS)	**0.33**	**0.30**	**0.34**	**0.83**	**0.86**	0.22	**0.51**	**0.90**	0.06	1.00			
Performance Measures	**Timed Up and Go (TUG)**	**-0.31**	**-0.62**	**-0.31**	**-0.36**	**-0.37**	**-0.32**	-0.26	**-0.42**	**-0.43**	-0.28	1.00		
	Chedoke-McMaster Stroke Assessment Scale (CMSAS)	0.20	**0.71**	**0.37**	0.20	0.10	0.11	0.01	0.21	**0.49**	-0.03	**-0.68**	1.00	
(CMSAS Stages)	**Stage of Hand (S HD)**	0.15	**0.55**	0.27	0.13	0.10	0.04	-0.02	0.21	**0.35**	0.00	**-0.59**	**0.88**	1.00
	Stage of Arm (S AR)	0.18	**0.64**	**0.31**	0.11	0.01	0.07	0.07	0.12	**0.45**	-0.09	**-0.57**	**0.88**	**0.84**
	Stage of Leg (S LG)	0.17	**0.79**	**0.39**	0.24	0.19	0.25	0.13	0.26	**0.55**	0.03	**-0.63**	**0.88**	**0.72**
	Stage of Foot (S FT)	0.12	**0.52**	**0.32**	0.02	-0.08	0.07	-0.14	-0.07	**0.43**	0.26	**-0.39**	**0.79**	**0.64**
	Shoulder Pain (SP)	0.11	**0.30**	0.11	0.16	-0.05	-0.02	-0.10	0.07	0.16	0.03	-0.23	**0.48**	0.19
	Stage of Postural Control (S PO)	0.22	**0.65**	**0.38**	**0.32**	**0.35**	0.18	0.14	0.43	**0.41**	0.24	**-0.82**	**0.80**	**0.67**
	Box and Block Test, hemiplegic hand (BBTH)	0.18	**0.71**	**0.46**	0.29	0.25	0.15	0.22	**0.38**	**0.47**	0.17	**-0.70**	**0.82**	**0.78**
	Box and Block Test, normal hand (BBTN)	0.24	**0.58**	**0.36**	**0.46**	**0.41**	**0.31**	0.29	**0.49**	**0.39**	**0.38**	**-0.65**	**0.46**	**0.34**
	Albert' s Test (ALB)	-0.09	-0.19	-0.16	**-0.40**	**0.41**	0.09	0.00	**-0.47**	0.04	**-0.44**	**0.30**	-0.25	**-0.38**
	OARS IADL component (IADL)	**0.39**	**0.77**	**0.40**	**0.54**	**0.45**	**0.32**	0.27	**0.61**	**0.49**	**0.43**	**-0.75**	**0.68**	**0.59**
	Barthel Index (BI)	**0.44**	**0.64**	**0.34**	**0.41**	**0.41**	**0.34**	0.30	**0.48**	**0.47**	**0.34**	**-0.92**	**0.59**	**0.49**
Confounders	**AGE**	**-0.32**	-0.22	-0.20	-0.19	-0.13	-0.07	-0.02	-0.07	-0.22	-0.06	**0.40**	-0.27	**-0.34**
	Geriatric Depression Scale (GDS)	**-0.45**	**-0.62**	**-0.50**	**-0.66**	**-0.65**	-0.09	**-0.33**	**-0.73**	**-0.33**	**-0.65**	**0.60**	**-0.47**	**-0.37**
	Charlson Comorbidity Index (CHAR)	-0.06	-0.18	-0.04	0.01	-0.04	-0.06	-0.09	-0.03	-0.09	0.04	0.24	-0.21	-0.10

Correlation Matrix continues next page

Bold values indicate significant correlations ($p<0.05$)

Pearson Correlation Coefficients, continued

	S AR	S LG	S FT	SP	S PO	BBTH	BBTN	ALB	IADL	BI	AGE	GDS	CHAR
General Health (GH)													
Physical Functioning (PF)													
Physical Role Limitations (RP)													
Emotional Role Limitations (RE)													
Social Functioning (SF)													
Bodily Pain (BP)													
Vitality (VT)													
Mental Health (MH)													
Physical Health Summary Score (PCS)													
Mental Health Summary Score (MCS)													
Timed Up and Go (TUG)													
Chedoke-McMaster Stroke Assessment Scale (CMSAS)													
Stage of Hand (S HD)													
Stage of Arm (S AR)	1.00												
Stage of Leg (S LG)	**0.75**	1.00											
Stage of Foot (S FT)	**0.66**	**0.74**	1.00										
Shoulder Pain (SP)	**0.31**	0.27	0.16	1.00									
Stage of Postural Control (S PO)	**0.53**	**0.75**	**0.56**	**0.33**	1.00								
Box and Block Test, hemiplegic hand (BBTH)	**0.79**	**0.72**	**0.58**	**0.33**	**0.67**	1.00							
Box and Block Test, normal hand (BBTN)	0.27	**0.50**	**0.30**	0.24	**0.61**	**0.67**	1.00						
Albert' s Test (ALB)	-0.15	-0.19	-0.13	0.05	**-0.39**	**-0.41**	**-0.46**	1.00					
OARS IADL component (IADL)	**0.52**	**0.70**	**0.39**	**0.31**	**0.78**	**0.72**	**0.73**	**-0.49**	1.00				
Barthel Index (BI)	**0.50**	**0.56**	**0.33**	0.23	**0.75**	**0.59**	**0.57**	-0.26	**0.76**	1.00			
AGE	-0.20	**-0.33**	-0.19	0.09	**-0.32**	**-0.30**	**-0.35**	0.20	**-0.39**	**-0.33**	1.00		
Geriatric Depression Scale (GDS)	**-0.35**	**-0.48**	-0.20	-0.23	**-0.64**	**-0.56**	**-0.61**	**0.58**	**-0.71**	**-0.60**	**0.33**	1.00	
Charlson Comorbidity Index (CHAR)	-0.09	-0.18	-0.23	-0.17	-0.29	-0.20	-0.29	0.03	**-0.35**	-0.28	**0.31**	0.03	1.00

Bold values indicate significant correlations (p<0.05)

APPENDIX E

Comparison of SF-36 Scores to United States Population Normative Values

Comparison of SF-36 Subsection and Summary Score Sample Values to United States Population Normative Values#

	Sample (n=44)				Population* (n=1000)			
	Mean	SD	Upper CI	Lower CI	Mean	SD	Upper CI	Lower CI
General Health	65.4	19.9	71.3	59.5	72.2	20.2	73.5	70.9
Physical Role Limitations*	49.4	39.4	61.0	37.8	81.2	33.8	83.3	79.1
Emotional Role Limitations	78.0	35.9	88.6	67.4	81.3	33.0	83.3	79.3
Physical Functioning*	60.5	30.2	69.4	51.6	84.5	22.9	85.9	83.1
Social Functioning	80.1	28.8	88.6	71.6	83.6	22.4	85.0	82.2
Bodily Pain	73.0	29.3	81.7	64.3	75.5	23.6	77.0	74.0
Vitality	53.6	23.2	60.5	46.7	61.0	20.9	62.3	59.7
Mental Health	75.3	21.8	81.7	68.9	74.8	18.0	75.9	73.7

	Sample Men (n=26)				Population Men (n=1055)			
	Mean	SD	Upper CI	Lower CI	Mean	SD	Upper CI	Lower CI
Mental Health Summary Score	54.0	8.8	57.4	50.6	50.7	9.6	51.3	50.1
Physical Health Summary Score*	41.7	9.6	45.4	38.0	51.1	9.4	51.7	50.5

	Sample Women (n=18)				Population Women (n=1412)			
	Mean	SD	Upper CI	Lower CI	Mean	SD	Upper CI	Lower CI
Mental Health Summary Score	50.4	14.9	57.4	43.4	49.3	10.3	49.8	48.8
Physical Health Summary Score*	41.2	13.2	47.4	35.0	49.1	10.4	49.6	48.6

	Sample Values, Ages 50-64 (n=13)				Population Values, Ages 55-64 (n=269)			
	Mean	SD	Upper CI	Lower CI	Mean	SD	Upper CI	Lower CI
Mental Health Summary Score	52.8	8.1	56.9	48.7	51.1	9.7	52.3	49.9
Physical Health Summary Score	45.8	11.5	51.6	40.0	45.9	11.3	47.3	44.5

	Sample Values, Ages 65-74 (n=15)				Population Values, Ages 65-74 (n=442)			
	Mean	SD	Upper CI	Lower CI	Mean	SD	Upper CI	Lower CI
Mental Health Summary Score	54.2	8.4	59.0	49.4	52.7	9.3	53.6	51.8
Physical Health Summary Score	39.5	9.5	45.0	34.0	43.3	11.2	44.3	42.3

	Sample Values, Ages 75+ (n=16)				Population Values, Ages 75+ (n=264))			
	Mean	SD	Upper CI	Lower CI	Mean	SD	Upper CI	Lower CI
Mental Health Summary Score	49.7	16.5	57.6	41.8	50.4	11.7	51.9	49.0
Physical Health Summary Score	38.9	12.1	44.7	33.1	37.9	11.2	39.3	36.5

SD= Standard Deviation; CI=90% Confidence Interval

*Indicates value significantly different from U.S. population normative values, $p<0.05$

United States population normative values taken from : Ware JE: SF-36 Physical and Mental Health Summary Scales: A User's Manual, The Health Institute, Boston, Massachusetts, 1994.

APPENDIX F

Plots of Mental and Physical Health Summary Scores against Performance Measures

Plots of Squared Mental Health Summary Score (MCSSQR) by Performance Measure for Women

```
 A=1, B=2, etc.
         Plot of MCSSQR*OARS IADL
         n=19
  SSQR |
  6000 +
       |
       |                        A
  4000 +               A A      A A
       |                       AA C
       |               A     A    A
  2000 +                          B
       |               A
       |     A    A   A
     0 +
       --+--------+--------+--------+-
         0        5        10       15

                     IADL
```

```
 A=1, B=2, etc.
         Plot of MCSSQR*Barthel
         n=19
MCSSQR |
  6000 +
       |
       |
  4000 +                        A A
       |                          A
       |                  A       A
  2000 +                          A
       |                        A
       |   A                      B
     0 +
       --+--------+--------+--------
        40       60       80       1

                   Barthel
```

```
 A=1, B=2, etc.
 Plot of MCSSQR*Timed Up & GO
          n=18
MCSSQR |
  6000 +
       |
       |     A
  4000 +     AAA    A
       |    DA
       |     AA    A
  2000 +     B
       |
       |      AA                    A
     0 +
       --+--------+--------+--------+-
         0       20       40       60

         Timed Up & Go
```

```
  A=1, B=2, etc.
  Plot of MCSSQR*Box & Block Test
  (hemiplegic hand) n=18
MCSSQR |
  6000 +
       |
       |                       A
  4000 + A    A       AA
       |                    AA AAA
       |             AA     A
  2000 +                  A  A
       |
       |    A     A   A
     0 +
       --+--------+--------+--------
         0       25       50

         Box & Block Test
         Hemiplegic Hand
```

```
A=1, B=2, etc.
   Plot of MCSSQR*Box & Block Test
   (normal hand) n=18
MCSSQR |
  6000 +
       |
       |                     A
  4000 +                A A A   A
       |                 A     ABA
       |                 A  A    A
  2000 +                 A      A
       |
       |       A  A        A
     0 +
       --+--------+--------+--------+-
         0       25       50       75

         Box & Block, normal hand
```

```
 A=1, B=2, etc.
            Plot of MCSSQR*Albert
                 n=18
MCSSQR |
  6000 +
       |
       |A
  4000 +AB A
       |CB
       |BA
  2000 +B
       |
       |A     A                  A
     0 +
       -+-------------+-------------
        0            20

        Albert's Test
```

Plots of Physical Health Summary Score (PCS) by Performance Measure for Women

```
 A=1, B=2, etc.   Plot of PCS*IADL.
                     n=19
 PCS |
  75 +
     |
     |                          A C
  50 +          A                 B
     |                A           A
     |              A   A   A A A A
  25 +    A           A         A
     |                A
     |
   0 +
     -+---------+---------+---------+-
      0         5        10        15

                 IADL
```

```
 A=1, B=2, etc.   Plot of PCS*Barthe
                     n=19
 PCS |
  75 +
     |
     |                              D
  50 +                            B A
     |                   A        A
     |                         A  B C
  25 +   A                     A    A
     |                            A
     |
   0 +
     -+---------+---------+---------+
     40        60        80        10

                 Barthel
```

```
 A=1, B=2, etc.  Plot of PCS*TUG.
   Plot of PCS*Timed Up & Go
                  n=18
 PCS |
  75 +
     |
     |   ABA
  50 +   A A A
     |     A     A
     |    BAB      A
  25 +    A                         A
     |       A
     |
   0 +
     -+---------+---------+---------+-
      0        20        40        60

   Timed Up & Go
```

```
 A=1, B=2, etc.
 Plot of PCS*Box & BLock
 Hemiplegic Hand    n=18
 PCS |
  75 +
     |
     |                A     A A A
  50 +          A          A    A
     |              A    A
     |A     A      AA       B
  25 +    A                   A
     |               A
     |
   0 +
     -+---------+---------+---------+
      0        25        50        75

      Box & Block, hemiplegic hand
```

```
 A=1, B=2, etc.
  Plot of PCS*Box & Block Test
  Normal Hand     n=18

 PCS |
  75 +
     |
     |                A     AB
  50 +         A             AA
     |                B
     |                 AAB   AA
  25 +       A             A
     |                 A
     |
   0 +
     --+------+------+------+------+--
       0     20     40     60     80

   Box & Block, normal hand
```

```
 A=1, B=2, etc.
        Plot of PCS*Albert's Test
                  n=18

 PCS |
  75 +
     |
     |D
  50 +AA                        A
     |AA
     |CAAA
  25 +A     A
     | A
     |
   0 +
     -+--------------+--------------+
      0             20             40

      Albert's Test
```

Plots of Squared Mental Health Summary Score (MCSSQR) by Performance Measure for Men

```
 A=1, B=2, etc.  Plot of MCSSQR*IADL.
                   n=25
MCSSQR |
  6000 +
       |
       |                            A
  4000 + A              A  A     B  A
       |         A  A            A  D
       |                   A     A  C
  2000 + A                       A  A
       |                   A        B
       |
     0 +
       --+--+--+--+--+--+--+--+--+--+-
         5  6  7  8  9 10 11 12 13 14

                     IADL
```

```
    A=1, B=2, etc. MCSSQR*Barthel
                n=25
MCSSQR |
  6000 +
       |
       |
  4000 +A                   A
       |                A
       |                        A
  2000 +            A
       |                A
       |
     0 +
       -+---+---+---+---+---+---+---
       65  70  75  80  85  90  95  1

                   Barthel
```

```
 A=1, B=2, etc.
    Plot of MCSSQR*Timed Up & Go
                n=25
MCSSQR |
  6000 +
       |
       |     A
  4000 +      BA B            A
       |    ADA A
       |    BAB
  2000 +    A A        A
       |   AA A
       |
     0 +
       -+-------------+-------------+-
        0            20            40

        Timed Up & Go
```

```
  A=1, B=2, etc.
    Plot of MCSSQR*Box & Block Test
    Hemiplegic Hand   n=25
MCSSQR |
  6000 +
       |
       |                        A
  4000 + A              B   B  A
       |               A    A AA  AA
       |             A    A    A AA
  2000 +               A      A A
       |                  A    A  A
       |
     0 +
       --+--------+--------+--------
         0       25       50       7

         Box & Block, hemiplegic han
```

```
A=1, B=2, etc.
Plot of Box & Block Test
Normal Hand   n=25
MCSSQR |
  6000 +
       |
       |               A
  4000 +      A   BA  AA
       |             A B AA A A
       |           A AA    B
  2000 +     A        A    A
       |            A   A A
       |
     0 +
       --+--------+--------+--------+-
        25       50       75       100

        Box & Block, normal hand
```

```
A=1, B=2, etc.
        Plot of MCSSQR*Albert
                n=25
MCSSQR |
  6000 +
       |
       |A
  4000 +D  A
       |F  A
       |C  B
  2000 +C
       |A     A       A
       |
     0 +
       -+-------------+-------------
        0             5            1

        Albert's Test
```

Plots of Physical Health Summary Score (PCS) by Performance Measure for Men

```
  A=1, B=2, etc.
          Plot of PCS*IADL
PCS           n=25
 60 +
    |                          A  B
    |              A     A        A
    |                             D
    |                 A           B
 40 +                          B
    |                          A  B
    |  A                 A     A  A
    |           A
    |  A                 A
 20 +
    ---+--+--+--+--+--+--+--+--+--+--
       5  6  7  8  9 10 11 12 13 14

                   IADL
```

```
 A=1, B=2, etc.
         Plot of PCS*Barthel
PCS         n=25
  60 +
     |                         A   B
     |                             C
     |                             D
     |                             C
  40 +                             B
     |                     A       B
     |             A               C
     |                 A
     | A               A
  20 +
     --+---+---+---+---+---+---+---+-
      65  70  75  80  85  90  95  100

                  Barthel
```

```
  A=1, B=2, etc.
   Plot of PCS*Timed Up & Go
PCS        n=25
 60 +
    |     AAA
    |    AA A
    |     AC
    |     AA   A
 40 +       A A
    |     AA   A
    |       BA       A
    |       A
    |       A               A
 20 +
    --+------+------+------+------+--
      0     10     20     30     40

      Timed Up & Go
```

```
    A=1, B=2, etc.
     Plot of PCS*Box & Block Test
     Hemiplegic Hand  n=25
PCS  60 +
        |                         AA A
        |                     AA     A
        |                   A        AAA
        |                A       A A
     40 +                        B
        |                   A A    A
        |             A A A      A
        |                A
        |A                       A
     20 +
        -+---------+---------+---------+-
         0        25        50        75

         Box & Block, hemiplegic hand
```

```
A=1, B=2, etc.
 Plot of PCS*Box & Block
 Normal Hand  n=25
 60 +
PCS |               A    B
    |             A  AA
    |                   AA AA
    |        A       A   A
 40 +                A  A
    |               AB
    |      A     B  A
    |              A
    |            AA
 20 +
    --+------+------+------+------+--
     20     40     60     80     100

     Box & Block, normal hand
```

```
A=1, B=2, etc.
        Plot of PCS*Albert's
              n=25
 60 +
PCS |B  A
    |A  A           A
    |C     A
    |C
 40 +B
    |B  A
    |C  A
    |A
    |A                             A
 20 +
    -+--+--+--+--+--+--+--+--+--+--+-
     0  1  2  3  4  5  6  7  8  9 10

     Albert's Test
```

APPENDIX G

Plots of Residual Values for Final Regression Models

```
                    Women's Model, Squared Mental Health Summary Score
                        Plot of Residual Values*Predicted Values

  Legend: A = 1 obs, B = 2 obs, etc.
          n=18
[illegible]duals
 2000 +
      |                                 A
      |                                                A
      |                          A            AA       A
    0 +----------B-------------------------A--A--A-----A------A---------------
      |                                      A                     A
      |                    A                                A
      |                                              A
-2000 +
      -+-------------+-------------+-------------+-------------+-------------+
       0           1000          2000          3000          4000          5000

                                      Predicted
```

```
                Women's Model, Physical Health Summary Score
                         Plot of Residuals*Predicted

Legend: A = 1 obs, B = 2 obs, etc.
        n=18
Residuals
 20 +
    |                                    A
    |      A                                     A       BA           A
    |                                        A
  0 +--------------------------------------A-----------A-----------A----------
    |               A                           A    A
    |
    |                                       A           A        A
-20 +                             A
    --+---------+---------+---------+---------+---------+---------+---------+-
     20        25        30        35        40        45        50        55

                                  Predicted
```

```
                Men's Model, Physical Health Summary Score
                          Plot of Residuals*Predicted

Legend: A = 1 obs, B = 2 obs, etc.
        n=18
Residuals
 20 +
    |                                                           A
    |                                                        A    A
    |    A                                    A           A  AA  A     A
  0 +-------------------------------A------A---------------------A----A-------
    |                                   A  A      A  A           B   A      A
    |                                                       A      A
    |
-20 +                                                      A
    -+-----------+-----------+-----------+-----------+-----------+-----------+
     20          25          30          35          40          45          50

                                    Predicted
```

nb: residual=observed value-predicted value