

HEALTH OF PEOPLE WITH SPINAL CORD INJURY IN SINGAPORE:
THE IMPLICATIONS FOR REHABILITATION PLANNING AND IMPLEMENTATION

by

SOCK HUI JOY TEO

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ABSTRACT

Background: Knowledge about the health of people living with spinal cord injuries (SCIs) in the community is lacking in Singapore.

Purpose: To describe the health of people with SCI in Singapore and formulate recommendations for long-term rehabilitation planning and implementation.

Methods: This was a cross-sectional descriptive study of people living with traumatic SCI in Singapore. Demographic data, injury information and information about SCI-related secondary impairments, chronic conditions and their associated risk factors, medical and hospital utilization, participation (Craig Handicap Assessment and Reporting Technique [CHART]) and life satisfaction (Satisfaction with Life Scale [SWLS]) were collected through telephone or in-person interviews. Participants were stratified according to presence or absence of a full-time live in carer, time since injury, injury type and participation in regular exercise. Post-hoc comparisons were conducted for these groups. The association between participation and life satisfaction was examined.

Results: On average, participants (50 men and 5 women) were aged 48.3 ± 16.54 years and had had their SCIs for 5 years. Three quarters (78.2%) had tetraplegia. The most prevalent SCI-related secondary impairments were pain, spasms, bladder problems, bowel problems and edema. The prevalence of chronic conditions and their associated risk factors was greater among the participants than reported for Singaporeans overall. The prevalence of diabetes and hypertension was 9.1% and 10.9%, respectively. Almost a quarter of participants were told by doctors that they were overweight and/or had high cholesterol.

One quarter (25.5%) of participants reported exercising regularly. The prevalence of binge drinking and daily smoking was 5.5% and 12.7%, respectively. Mean CHART scores ranged between 32.2 and 88.4 with lowest scores in the 'occupation' dimension. The mean SWLS score was 13.9. Participation and life satisfaction scores were lower than those reported for similar populations cross-culturally.

Conclusion: People with SCI in Singapore may be less healthy than the population overall. Our findings support the need for a registry and database to help track the changing needs of this population over time with the aim to increase the quality of life of people with SCI in Singapore and, in turn, help minimize long-term social and economic burdens for the country.

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GLOSSARY

Health: Health is to have developed the abilities and dispositions that members of one's culture typically develop, and be able to use them, in acceptable circumstances; and health is to experience positive moods and sensations, the kinds that have internal causes.¹

Chronic conditions: A group of health conditions of long duration and generally slow progression. They include cardiovascular disease (mainly heart disease and stroke), cancer, chronic respiratory diseases, diabetes and others (e.g., mental illness and bone and joint disorders). In this study, chronic conditions will refer to heart disease, stroke, diabetes, arthritis, asthma and cancer.

Risk factors: Chronic conditions share three common behavioral risk factors – unhealthy diet, physical inactivity and tobacco use.² The risk factors examined in this study will include cigarette smoking, alcohol consumption, hypertension, increased blood cholesterol or lipids, and being overweight.

Participation: Involvement in life situations.³ In this study, objective participation will be measured i.e. the degree to which respondents fulfilled the roles typically expected of able-bodied members of their society.⁴

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INTRODUCTION

BACKGROUND AND RATIONALE

Disability and Health

The Enabling Masterplan 2007-2011⁵ is an initiative of the Singapore government to develop a society where people with disabilities “are given the opportunity to become equal, integral and contributing members of society through effective intervention services and quality education, equal opportunities for people with disabilities in employment and the opportunity to live with dignity in the community.” In Singapore, a person with a disability (PWD) is defined as one “whose prospects of securing, retaining places and advancing in education and training institutions, employment and recreation as equal members of the community are substantially reduced as a result of physical, sensory, intellectual and developmental impairments”.⁶ This definition is largely based upon the medical model which attributes disability to sickness or defects in the body systems.⁶ However the Singapore government recognizes that disability is not merely a function of limitations in bodily structures and functions as evidenced in the report of the Enabling Masterplan 2007-2011 that acknowledges the contribution of the physical, attitudinal, political and social environments towards disability.

This view is in agreement with the International Classification of Functioning, Disability and Health (ICF)³ put forth by the World Health Organization (WHO) in 2001. The ICF measures disability from three perspectives, namely the body, individual and society. It also considers the context in which the individual lives. From the perspective of the body,

the term impairment is used to describe problems with body function or structure. Activity limitation is the term used when the individual has a problem with a specific task or action. From the societal perspective of disability, emphasis is placed upon the involvement of the individual in life situations. This involvement is also known as participation. The ICF framework takes into consideration the dynamic interaction between a person's individual characteristics and the environment. Although the ICF has become an established classification system for disability and functioning, its relationship to health is less apparent. The WHO⁷ defines health as a "state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." The ICF model does not reflect how the interaction of limitation in body structure and function, activity, participation and the contextual factors influence an individual's physical, mental and social well-being. The model does not explain the meaning of well-being and how completeness of well-being in all of its dimensions is to be achieved.

There are various theories of health and approaches designed to increase health that have been proposed in the literature. Concepts such as goals, abilities, function, happiness, autonomy and well-being have been used to formulate theories of health and its definition. Christopher Boorse's species-typical theory defines health in terms of normal functional ability, where normal functional ability is calculated statistically with respect to an age group of a sex of a species.⁸ This approach basically views health as the absence of disease which various authorities have argued against since the time of Hippocrates.

Lennart Nordenfelt⁹ and David Seedhouse¹⁰ developed their theories around the concept of the ability to achieve goals. Nordenfelt⁹ included in his welfare theory an affective component which states that the vital goals (which is relative to each individual) achieved would produce the minimally necessary amount of happiness for the individual. In his foundations theory, Seedhouse¹⁰ defined health as the “state of the set of conditions which fulfill or enable a person to work to fulfill his or her realistic chosen and biological potentials. Some of these conditions are of the highest importance for all people. Others are variable dependent upon individual abilities and circumstances.” There are four central conditions which he proposes are important for all people to be able to exercise autonomy in choosing and achieving goals. Health in this theory is a means to an end and does not include an affective component.

Per-Anders Tengland¹ has proposed a theory of health which appears to have included elements of all the above theories. Health in his theory has two-dimensions, ability and well-being.¹ “Health is to have developed the abilities and dispositions that members of one’s culture typically develop, and be able to use them, in acceptable circumstances; and second, health is to experience positive moods and sensations, the kinds that have internal causes.” The abilities referred to in this theory include basic ones that are developed and acquired just by growing up and living in society such as walking and talking (intentional); seeing and hearing (unintentional). An individual should also have the ability to acquire new competencies. The ‘ability’ dimension of the theory also includes having certain dispositions, motivations and states of mind that would be developed by the general population. Dispositions are automatic reactions or changes to

events in the environment, such as the ability to experience emotions and to manage a certain amount of stress. Motivation is the energy or drive that gives us the desire to act. An individual while growing up should also generally have developed mental states which enable him to comprehend reality and provide him with a sense of being able to perform tasks (self-confidence). The 'well-being' dimension in this theory of health refers to moods and sensations derived from an internal cause (e.g. feeling full of energy or strong) and not sustained by an external trigger or event (e.g., birth of a baby) (health-related well-being).

Using this two-dimensional theory of health, a chronic condition such as hypertension would be seen to reduce an individual's health, as the individual has lost the ability to be normotensive and to minimize their health risk. A condition such as spinal cord injury (SCI) which can result in paralysis of the lower limbs is perceived as reducing an individual's health as the individual no longer has the ability to walk – an ability developed through growth. However the individual can still maintain good health as he or she has other abilities, dispositions etc. which the SCI did not affect. He or she is also still capable of experiencing the positive moods and sensations associated with health.

This theory could provide a way to relate the ICF to health. Measures of limitations in body structure and function, activity and participation would reflect the 'abilities' dimension of health, i.e., the degree to which an individual possess the abilities, dispositions that people typically develop in a particular society (thus also considering environmental factors). Contextual factors encompassed in the ICF include both environmental and personal factors. Personal factors may represent health-related well-

being given that moods and sensations of internal cause (e.g. depression and despair) may affect an individual's abilities.

Health of Singaporeans

Singapore's rapid industrialization has resulted in great progress in the economy, infrastructure, science and technology, which has translated into an advanced healthcare system. Singaporeans generally enjoy good health. The infant mortality rate in Singapore is 2.1 per thousand live births and the overall life expectancy is 80.6 years.¹¹

Like in other high-income countries, the healthcare system in Singapore is facing the challenge of preventing and managing chronic non-communicable diseases such as coronary heart disease, stroke, cancer and diabetes.¹² These chronic conditions, also known as lifestyle conditions, share similar risk factors which include physical inactivity, smoking, alcohol consumption and poor nutrition. In Singapore these conditions are the leading causes of morbidity and mortality.¹¹ In response to the challenge of such chronic conditions, "a multipronged disease management approach has been adopted, consisting of patient and family education, promotion of self management, clinical care process changes, use of various clinical tools and communication plans between caregiver and patient, feedback on patient outcomes, and an information technology infrastructure to support these activities."¹³ The Singapore Health Promotion Board has implemented various programs and campaigns to promote healthy lifestyle changes in nutrition, physical activity, stress management and tobacco use.¹⁴

The National Health Survey conducted in 2004 showed declines in the prevalence of diabetes, hypertension and their associated risk factors (blood cholesterol, cigarette smoking and physical inactivity) when compared to the rates in 1998.¹⁵ Though overall this is encouraging, the report also highlights other areas that remain a concern. For example, the prevalence of cigarette smoking had remained unchanged among women in general, and had increased among young women between 18 and 29 years of age. Regular alcohol consumption had become more prevalent (2.6% in 1998; 3.2% in 2004) and the prevalence of binge drinking increased from 5.1% to 9.6%.

The aging population in Singapore poses health-related challenges in the years ahead. Increasing age is associated with an increase in the number of chronic conditions.¹⁶ Older age is also associated with increasing functional deficits and physical dependence. A recent study on elderly people in Singapore reported increase in the prevalence of functional disability (defined as needing assistance with at least 1 out of 10 items on the Barthel Index) compared to previous years.¹⁷ The changing demographics of the population in Singapore has stimulated increased research in the past 2 decades into the health of the elderly and necessitated the development of government policies and strategies¹⁸ to address the change.

Health of People with Disabilities in Singapore

Another subgroup of society in Singapore who, until recently, has been given little attention is people with disabilities (PWDs). There are no official statistics on the prevalence of disability in Singapore and there is a paucity of information on the health status and quality of life of PWDs. Literature on the outcomes of rehabilitation in people following injury or disease focus mainly on impairments and activity limitations shortly post discharge.¹⁹

The lives of those with disabilities in Singapore may be more challenging than what is actually acknowledged. A study of young adults with cerebral palsy after they had left the support of the special needs school system showed that they were more disabled, had decreased healthcare access and were more socially isolated than the students still in the special needs schools.²⁰ In a study that evaluated an occupational therapy return to work program, 34% of clients with stroke who were referred to that program returned to the open market. However, the number of clients with stroke referred to that program grossly under-represented the incidence and prevalence of survivors of stroke in the country overall.²¹ In another study on employment after discharge from an inpatient rehabilitation unit, 45.6% of clients with mild to moderate physical disability were reported to be employed 6 months after being discharged from hospital.²² Return to work however is not a sufficient measure of the success of rehabilitation or community reintegration.

To achieve the vision of the Enabling Masterplan 2007-2011,⁵ a more comprehensive investigation into the health and lifestyle of PWDs in Singapore is indicated.

An understanding of the status and needs of this unique population is needed to ensure that scarce healthcare and rehabilitation resources are allocated to optimize their cost benefit ratio.

Healthcare System and Financing in Singapore

The Singapore healthcare system comprises of a public and private sector, together with rising standards of living, housing, education, medical services, safe water supply and sanitation, and preventive medicine.²³ Most of primary healthcare (80%), which includes preventive medicine and health education, is provided by private general medical practitioners. The remaining 20% is provided by government outpatient polyclinics. Polyclinics are government-subsidized one stop health centers that provide a range of services including health screening, immunizations, post-hospitalization follow-up care and outpatient medical services.

Acute hospital care in Singapore is managed largely by the public sector. There are seven public hospitals of which five are general hospitals, one a women and children's hospital and one psychiatry hospital. The general hospitals provide inpatient services, outpatient specialist care, and 24-hour emergency services. There are also several specialist medical centers such as the National Cancer Centre and National Neuroscience Institute. Seventy-two percent of hospital beds are in the public hospitals and specialty centers. About 80% of the public hospital beds are subsidized up to 75% and the remaining beds subsidized 20% or not at all. The amount of government subsidy affects the type of

ward accommodation received (e.g., six-bed room, private room, presence or absence of air-conditioning), not the quality of medical services.

Step-down community-based and residential care, such as community hospitals, nursing homes, hospices and rehabilitation centers contribute to the long-term care needs of Singaporeans. Many of these services are provided by voluntary welfare organizations (VWOs). A VWO is an organization that provides welfare services and/or services that benefit the community at large and is not profit-making.²⁴

With regards to the financing of health and medical services, a policy of “co-payment” is practiced by the government.²⁵ In addition to large government subsidies, several medical financing schemes are available to assist Singapore residents to “co-pay” medical fees. They include MediSave, MediShield, ElderShield and MediFund. MediSave is a compulsory medical savings account to which both the individual and his or her employee contribute to monthly. MediSave funds enable most Singaporeans to cover their portion of medical fees. MediShield is a government managed low-cost catastrophic medical insurance scheme. ElderShield is a severe-disability insurance scheme. Finally, MediFund is a government endowment fund used to cover medical expenses of very needy patients who are unable to pay their medical bills, despite heavy subsidies.

Migrant Domestic Workers in Singapore

There are currently about 150 000 women migrant domestic workers/helpers in Singapore. They mainly come from Indonesia, Philippines and Sri Lanka.²⁶ These women live in the homes of their employers. Typically their jobs include household duties and childcare. They are also employed to care for the elderly and people with disabilities. Approximately one in seven households employs a migrant domestic worker.²⁶ In addition to paying the wages of their foreign domestic helper, employers are required to pay a monthly levy to the government.²⁷ Levy concessions can be obtained under several conditions. If an employer or his or her family member has a disability which results in assistance required for ADLs, he or she will be eligible for this levy concession.²⁸

Issues of domestic worker abuse have received greater attention in recent years. The Human Rights Watch published a report in 2005 calling for measures to be taken to end this abuse in Singapore.²⁶ One of the issues raised by this report was the exclusion of domestic workers from the Employment Act. A consequence of this is that the hours of work, weekly rest days, termination of contract, maternity benefits, and other labor protections are not regulated and left to be determined by the employment agency or employer. The Human Rights Watch²⁶ reports that poorly defined work responsibilities, long work hours, infrequent or lack of rest days, paid vacation days or sick days and few termination of employment protections are typically reported problems faced by migrant domestic workers.

Epidemiology of Spinal Cord Injury

A recent literature review, which included studies published between 1995 and 2005, on the epidemiology of SCI worldwide included two studies on the prevalence of SCI and 17 studies on the incidence.²⁹ Of the two studies on prevalence, one was conducted in Australia³⁰ and the other in Finland.³¹ The prevalence rates of SCI in these two countries were reported as 681 and 280 per million inhabitants respectively. In the United States, an estimated 255,702 people, with a range of 227,080 to 300,938 people, were living with a SCI in 2007.³² In Canada, the incidence estimate for SCI is 35 per million per year, which works out to about 900 Canadians a year who experience a SCI.³³ The estimated global incidence of SCI is between 10.4 per million per year and 83 per million per year when individuals who died before hospital admission were excluded.²⁹ These statistics however have mainly been collated from high-income countries in North America and Europe. There is scarce information on the prevalence and incidence of SCI in South America, Asia and Africa.²⁹

More men than women succumb to SCIs.²⁹ Trauma is the main cause of SCI, of which motor vehicle accidents and falls contribute a large proportion.³⁴⁻³⁷ Recent trends show that the frequency of falls as a cause of SCI is increasing together with an increase in the mean age at time of injury.^{30, 35} This trend appears to be congruent with aging of the general population in many high-income countries³⁸ and improved healthcare in the acute and subacute stages of injury.

The consequences of a SCI are frequently severe and permanent. The resulting impairments of SCI are classified by the American Spinal Injury Association (ASIA) International Standards for Neurological Classification of Spinal Cord Injury which is based on the assessment of the residual sensory and motor function after SCI.³⁹ SCI can be broadly categorized into four groups: incomplete paraplegia, complete paraplegia, incomplete tetraplegia and complete tetraplegia. The frequency of each type of injury varies in the literature with more recent studies reporting an increase in the occurrence of tetraplegia.²⁹ This is true in Canada with an increase in incidence of tetraplegia from 25% to 46% between the 1970s and 1999.³⁴ Within the Model Spinal Cord Injury System in the United States, incomplete tetraplegia, presents as the most common SCI (34.1%) followed by complete paraplegia (23.0%), complete tetraplegia (18.3%) and incomplete paraplegia (18.5%).³²

Outcomes of Spinal Cord Injury

The outcome of SCI is reflected by the available immediate medical and surgical care as well as changes in functional status, neurologic status and overall health status. According to the WHO, the rehabilitation process aims to provide the individual with the necessary skills to achieve his/her optimal mental, physical, cognitive and social functional level. Independence and self-determination are the goals of rehabilitation. At the onset of the rehabilitation process following an acute SCI, an estimate of the potential level of functional independence that may be achieved by the individual is based on the individual's motor level of injury.⁴⁰ This estimate is used to help determine the functional

goals of the rehabilitation process. These goals are also influenced by age, sex, comorbidity and the client. The Clinical Practice Guidelines published by the Consortium of Spinal Cord Medicine describes the expected functional independence outcomes for each motor level of injury together with expected Functional Independence Measure (FIM) scores.⁴¹

Generally, individuals with SCI are expected to show improvement in functional status as reflected by FIM scores on discharge from inpatient rehabilitation when compared with admission scores, with greater improvements seen for individuals with less severe impairments.⁴² Based on the ASIA impairment scale (AIS) which consists of five categories, from A (complete) to E (no neurological deficit), about half of people with SCI classified as AIS B (sensory incomplete) or C (motor incomplete) can expect to improve by at least one grade in the first few months post-injury.

Ambulation is a priority goal of rehabilitation for most individuals with SCI. Although prediction of whether an individual will regain ambulatory function necessarily requires consideration of many variables, some factors can augment this prediction. For people with motor complete and incomplete quadriplegia, quadriceps strength, pin-prick sensation, and light touch sensation below the level of the lesion can predict ambulation outcome (non-ambulatory, exercise, household or community ambulatory).⁴³ In a study⁴⁴ that examined the injury factors that predict ambulation at discharge (FIM \geq 3, i.e. moderate assistance), individuals who had motor incomplete injuries on admission (AIS C and D) were more likely to walk at discharge than those who had motor complete injuries

(AIS A and B). More people with injuries classified as AIS D were ambulatory at discharge than those with AIS C injuries. Injury level (paraplegia vs. tetraplegia) among those who had AIS C or D injuries did not influence ambulatory status at discharge. For those with AIS D injuries, being over 50 years of age adversely influenced the potential for ambulation.

Long-Term Medical and Lifestyle Issues Associated with Spinal Cord Injury

Medical conditions secondary to SCIs such as pressure sores and urinary tract infections are common.⁴⁵⁻⁴⁷ These conditions are also associated with greater risk of mortality.⁴⁸ In a study of health behaviors in people with SCI,⁴⁹ 75% of their study sample had at least 4 of 13 secondary conditions (i.e., bladder problems, bowel problems, spasms, pain, oedema, pressure sores, increasing weight, excessive sweating, contractures, breathing/respiratory tract problems, neurogenic heterotopic ossification, low blood pressure, and thrombosis) within 12 months. Pressure sores were the most common problem, with 25-30% of the sample having at least one within first five years of injury. Up to 80% were likely to have experienced pressure sores requiring medical attention over their lifetimes.⁴⁹

The health of people with SCI is influenced by these secondary health conditions. In a study examining the influence of associated SCI conditions with health status, bowel, bladder, and/or sexual dysfunction, neuropathic pain, decreased motor function, and spasticity negatively affected health status (measured by the 36-Item Short Form Health Survey [SF-36]) of people with SCI resulting in central cord syndrome (greater neurological deficit in the arms than the legs).⁴⁷ Another study⁴⁶ reported that an increase in prevalence

of secondary health conditions in people with SCI is associated with a decrease in perceived health status although variations existed across health conditions and type of SCI (tetraplegia vs. paraplegia). However, despite the high prevalence of secondary health conditions, about two-thirds of the participants perceived their health as excellent (11%) or good (54%). In a 10-year longitudinal study of health-related outcomes following SCI, participants did not perceive health problems to be a major concern.⁵⁰

Chronic conditions such as cardiovascular disease (mainly coronary heart disease and stroke)^{51, 52} and diabetes⁵¹ also pose problems for people with SCI. A review of cardiovascular disease (CVD) in SCI reported the prevalence of CVD to be consistently higher than that in the ambulatory population.⁵³ CVD is also a leading cause of mortality and morbidity among people with SCI.⁵³ Heart disease has been shown to increase the risk of death more than three fold in people with SCI and circulatory diseases reported to be the underlying cause of about 40% of deaths.⁵⁴

In a study of veterans with SCI or disorders (SCI/D),⁵⁵ the prevalence of diabetes was higher among this population than the population at large (20% vs. 6.7%, $p < 0.001$) but similar to other veterans (21%). The findings of this study however suggested that diabetes may have an earlier onset in people with SCI/D. The study also reported that veterans with SCI/D and diabetes had a greater risk of experiencing other chronic conditions than veterans with SCI/D but without diabetes. For example, a veteran with a SCI/D and diabetes would have 2.8 and 2.7 times the risk of having coronary heart disease and myocardial infarction, respectively, than a veteran with SCI/D without diabetes. This

finding is supported by another study on a similar population.⁵¹ Smith, LaVela and Weaver⁵⁶ examined the impact of chronic health conditions and health behaviors on the health-related quality of life (HRQoL) of veterans with SCI and reported that the most common chronic health condition was hypertension (40.7%) followed by diabetes (15.3%) and coronary heart disease or myocardial infarction (11%). Chronic conditions negatively impact HRQoL.⁵⁶

Chronic conditions like CVD and diabetes share common risk factors. They include both physiologic risk factors such as insulin resistance, hyperlipidemia, hypertension and obesity as well as behavioral risk factors, such as reduced physical activity, smoking and alcohol consumption. These risk factors are accentuated in people with SCI.^{52, 53} In an in-depth review on obesity after SCI, Gater⁵⁷ suggested that 2 of every 3 individuals with SCI are likely to be obese and at risk for its metabolic consequences including cardiovascular inflammation, hyperlipidemia, insulin resistance, hypertension and thromboemboli.

People with SCI are considerably less active than people without such injury.⁵⁸ Though paralysis as a result of SCI necessarily places some restrictions on the individual, physical activity within one's means still has positive effects on the risk factors of CVD in people with SCI⁵⁹ as well as on the other risk factors for other conditions. In a study of patterns of alcohol consumption in people with SCI, 59.8% were reported to drink alcoholic beverages, and, of those, 23.9% reported alcohol abuse.⁶⁰ This latter group reported more pain and reduced satisfaction with life. Smith⁵⁶ reported the prevalence of binge drinking in the past 30 days to be 10.7% and smoking to be 19.5%. As in the general populations

without SCI, smoking is associated with increased all cause mortality⁶¹ and negatively affects most organ systems and their function.^{56, 62-64} Alcohol consumption is also associated with increased risk of mortality.⁶¹

The risk factors that are associated with chronic conditions have also been shown to be associated with other SCI-related secondary health conditions. For example physical activity has been reported to have a protective effect on the development of pressure sores while smoking increases the risk of their development.⁶³

Due to the large number of medical issues associated with SCI it is not surprising that medical and hospitalization utilization is more frequent in this population than in the general population. In a study on the health-related outcomes of people with SCI, only 23% of respondents reported not having consulted a medical practitioner in the first 6 months following discharge from hospital and 11% had consulted with one more than 10 times over that time frame. Medical consultation tended to peak 24 months post-discharge.⁵⁰

Participation Following Spinal Cord Injury

Despite the physical impairments of the injury, many survivors of a SCI have the potential to maintain quality of life and participate in various life situations.⁶⁵ Participation is often seen as the ultimate goal of rehabilitation. The conceptualization of this construct has evolved over time and is multifaceted. Broadly speaking, participation includes both the perceptions of society (objective participation) and the individual (subjective participation)⁶⁶ on the individual's involvement in life situations.

The assessment of participation is fraught with complexities. Objective participation alone involves more than determining the various life situations that the individual is or is not involved in but could also involve how much time is spent in each area, how much and the type of assistance they require for involvement and the barriers and facilitators to involvement. The inclusion of the subjective aspect of participation involves looking at the satisfaction the individual derives from involvement in each life situation, the perceived amount of choice in each situation, satisfaction with those choices and the positive or negative affect associated with involvement.

A widely used tool to measure objective participation in the SCI population is the Craig Handicap Assessment Technique (CHART).⁴ The goal of the CHART is to assess the extent of deviation reported by an individual with a disability, from the capacity to fulfill roles that is reported by people without disabilities. Results from studies using the CHART with individuals with SCI have reported the potential for high levels of participation across dimensions of physical independence, mobility, occupational status, social integration and economic self-sufficiency^{4, 66, 67} irrespective of injury level and completeness of injury. In other words, people with SCI have the potential to fulfill life roles to similar degrees as people without disabilities.

The Assessment of Life Habits (LIFE-H) is used to assess the quality of participation by assessing the manner (difficulty encountered and amount of assistance required) in which people carry out daily activities and social roles, as well as their associated satisfaction.⁶⁸ These daily activities and the activities that comprise social roles are known

as 'life habits', i.e., "those habits that ensure the survival and development of a person in society throughout life."⁶⁸ Based on this measure,⁶⁹ people with SCI experience disruption in more than half (58%) of life habits, according to predetermined criteria. In daily activities categories, all life habits (100%) related to personal care and mobility met the criteria of disruption. Among social roles, the life habits related to education, recreation, community and employment were the most disrupted. In line with the results of studies that assessed participation using the CHART, this study also reported less disruption in life habits with a decrease in level and severity of injury. This study however did not assess the satisfaction associated with accomplishment of these life habits.

The Impact on Autonomy and Participation Questionnaire (IPA)⁷⁰ is a recently developed tool that aims to evaluate the subjective quality of participation. In addition to the extent of perceived participation, the IPA also assesses the perceived problems associated with participation in 5 domains, namely 'autonomy indoors', 'family role', 'autonomy outdoors', 'social relations' and 'work and education'. The application of the IPA to people with SCI has shown they largely perceive their participation as fair to very good in the domains of 'autonomy indoors' (80% or more) and 'social relations' (more than 90%).⁷¹ Restrictions in participation were reported in 'autonomy outdoors', 'family role' and 'work and education'. In the same study, associations between perceived participation and problems with participation were reported.

Employment is an area in which people with SCI experience particular participation restriction regardless of whether objective or subjective participation is of interest.^{66, 69, 71-75}

The rate of return-to-work (RTW) varies widely depending on various factors including the definition of work used, the population studied and the time since injury.

Much research has been done around the factors associated with RTW with much of the focus centering around demographic, injury-related and functional independence variables. There is evidence too that factors external to the individual, such as government policies have bearing on employment outcomes.⁷⁶ Higher educational level appears to be a consistent predictor of RTW.⁷⁷⁻⁷⁹ Greater functional independence in self-care and mobility in the community has also been associated with higher likelihood of RTW.⁷⁹⁻⁸¹ In addition, specific skills, such as wheelchair capacity has been found to increase the likelihood of an individual with a SCI to RTW after adjusting for age, gender, lesion level and education.⁸² Vocational services also have an important role to play in assisting people with SCI to RTW. In a large study among vocational rehabilitation agencies in USA, job placement services, work disincentives and case expenditures were the most important predictors of employment outcomes.⁸³ Physical restoration rehabilitation services, substantial counseling and assistive technology services also contributed to positive employment outcomes in this study.

In accordance with the multifaceted nature of participation, various factors influence the participation of people with SCI. They include personal factors such as emotional distress^{72, 84} and locus of control,⁸⁵ demographic and injury-related factors such as physical impairments, pain, and functional ability^{75, 86-89} as well as environmental factors

such as social support, accessibility, transportation, financial support and access to resources and advocacy.^{71, 75, 90-92}

The construct of participation is important as it relates to life satisfaction and quality of life. Participation appears to mediate the effect of demographic, injury-related, and environment factors on life satisfaction and quality of life. Participation's positive association with life satisfaction^{87, 88, 93, 94} and quality of life^{88, 95, 96, 97} has been well established.

Spinal Cord Injury in Singapore

The population of people with SCI in Singapore is small. A study performed in 1987 provides the only estimate of the incidence of SCI, 27 per million per year.⁹⁸ In contrast to that reported in the North American and European literature, the evidence for the outcomes of SCI rehabilitation in Singapore is scarce and limited to the immediate post-rehabilitation phase.^{37, 99, 100} This study examines the health of people with SCI living in the community in Singapore with a focus on the secondary impairments associated with SCI (e.g. pressure sores and urinary tract infections), chronic conditions and their associated risk factors, medical and hospital utilization, participation and life satisfaction. Secondly the findings are used to inform the proposed formulation of a longitudinal data base related to health for people in Singapore living with SCIs, and to make recommendations for rehabilitation planning and implementation.

STUDY AIMS

With respect to people in Singapore living with SCIs:

Primary Aims

- i. To determine the prevalence of secondary impairments.
- ii. To determine the prevalence of chronic conditions and their associated risk factors.
- iii. To determine the frequency of medical and hospital utilization.
- iv. To determine the degree of participation.
- v. To determine general life satisfaction

Secondary Aims

- i. To inform the development of a longitudinal data base related to health for people in Singapore living with SCIs
- ii. To inform and make recommendations for rehabilitation planning and implementation

METHODS

ETHICAL APPROVAL

Ethical approval was obtained from the National Health Group (NHG) Domain Specific Review Boards in Singapore and the UBC Research Ethics Board (Appendix A).

RESEARCH DESIGN

This was a cross-sectional descriptive survey conducted by telephone and in-person interviews.

RECRUITMENT

The NHG is the governing body of a number of healthcare institutions in Singapore including Tan Tock Seng Hospital (TTSH). Demographic and contact information of individuals who had sustained a traumatic SCI and had undergone inpatient rehabilitation at Tan Tock Seng Rehabilitation Centre (TTSH-RC) between January 2000 and May 2009 was extracted from the NHG database. ICD-9 codes for SCI with and without vertebral fractures (80600 to 8069 and 95200 to 9529 respectively) and spinal surgery (8100 to 8109 and 0353) were used to extract this information. The list obtained formed the sampling pool for this study. Demographic and contact information for 260 individuals were obtained.

Letters were sent to approximately 50 potential participants in random order every two weeks from the commencement of the study. The letters described the purpose of the study, included a brief description of what participation entailed and to expect a telephone

call from the researchers to request their participation in the study. Interview questions were also included. Four survey team members made telephone calls to invite participation at least 48 hours after the initial letters were sent. Up to three attempts were made to contact each potential participant.

The team member verified the invitation had been received, screened for eligibility, then invited individuals to participate in the study. Individuals were included in the study if they had sustained a SCI due to trauma (e.g. road traffic accident or fall), were able to communicate in English, the language of administration in Singapore, or had a proxy able to communicate in English on their behalf (preferably living with the participant), were 21 years of age or older and were residents of Singapore (citizens or permanent residents). Individuals with cognitive impairments affecting their ability to receive, process and express information were excluded from the study. To screen for the presence of cognitive impairment, questions about the potential participant's date of birth, age, date of admission and discharge from hospital and length of stay were asked. The answers given by the individual were corroborated against this information extracted from the NHG database. In addition, the individual was asked about the presence of an acquired brain injury or problems with memory.

After ascertaining that the individual met the inclusion criteria, the survey team member reiterated the purpose of the study, explained the study procedure and answered any questions the individual may have had regarding the study. Security measures for protecting the respondent's confidentiality were described. Individuals were given the

option of participating in the study through a telephone interview or an in-person interview at a location convenient for them.

For those who chose the telephone interview option, verbal consent was obtained and recorded. A copy of the documentation of verbal consent was sent to each participant following the interview. For participants who chose the option of an in-person interview, the consent process was repeated on the day of the interview, and written consent obtained. All participants were informed that they were at liberty to discontinue the interview at any point. The interview was structured, with questions read verbatim and repeated as necessary. Each interview lasted about 30 minutes.

Participants were informed that they would receive a \$10 taxi voucher as a token of appreciation before commencing the interview. They were also given the opportunity to indicate if they would like to receive a summary of the results of the study on its completion.

OUTCOME MEASURES

The questionnaires consisted of 111 closed-ended questions (Appendix E). Demographic data collected included gender, date of birth, ethnic group, marital status, highest level of education achieved, employment status, and type of residence. Information on the cause of the injury, the resulting impairments (paraplegia or tetraplegia) and the time since injury was recorded.

Information on chronic conditions and their associated risk factors was recorded using questions extracted from the Singapore National Health Survey 2004.¹⁰¹ The questions gathered information on comorbidity including the presence and management of diabetes and hypertension. Individuals were also asked if they had ever been told by a doctor that they had had a heart attack, stroke, high blood cholesterol, asthma and/or are overweight. In addition, information on the individual's physical activity, cigarette smoking and alcohol consumption habits was recorded. Additional questions on sleep and stress were included given that these factors can contribute to an individual's health and the manifestation of chronic conditions.^{102, 103-105}

Based on the published literature,^{49, 63, 106} a list of 13 SCI-related secondary impairments was identified. Study participants were asked if they had any of these impairments in the previous 12 months.

To determine medical and hospitalization use, participants were asked how many times they visited a general medical practitioner or specialist in the previous 3 months and how many times they had been hospitalized in the previous 12 months.

The CHART⁴ was used to measure participation. The CHART is a measure of objective participation, which means it "collects information on the degree to which the respondent fulfills the roles typically expected from people without disabilities."⁶⁶ The CHART was chosen for use in this study as the information it provides is important in the Singaporean context. This tool provides information on possible inequalities in health and opportunities for participation between people with SCI and the general population. This

information could provide a basis for allocating resources to promoted greater inclusiveness of people with SCI within Singaporean society and increase their participation.

The CHART encompasses 6 dimensions which include physical independence, mobility, occupation, social integration, economic self-sufficiency and cognitive independence. For each CHART dimension, a score ranging from 0 to 100 is obtained. A higher score means greater social and community participation.¹⁰⁷ The CHART was initially designed for people with SCI. The test-retest reliability coefficients for the individual dimensions of the CHART ranged between 0.80 and 0.95.⁴ Validity of the CHART has also been established for this population.⁶⁷ Reliability has also been established for responses via proxy,¹⁰⁸ with statistically significant subject-proxy correlations between 0.28 and 0.80. As the CHART has been widely used in studies on people with SCI internationally,^{65, 66, 89, 109} a large pool of data exists for comparing participation between survivors of a SCI in Singapore and other countries.

The Satisfaction With Life Scale (SWLS) was used as a measure of an individual's cognitive-judgmental (vs. affective) aspect of subjective well-being.¹¹⁰ The SWLS has been used frequently in populations with SCI.^{90, 92, 94}

INTERVIEWER TRAINING AND PILOT PROCESS

Prior to commencement of the study, the questionnaire was piloted to assess the ease of its administration and clarity of the questions so that any problems in these areas

could be addressed in advance. Standardization of the administration of the questionnaire by the four survey team members was achieved as follows.

1. The survey team members discussed the interview, responses and interpretation.
2. A simulated interview was conducted during which one member performed the interview while the other three interviewers observed the process. All survey team members recorded the answers to the interview questions. Answers were compared and discussed.
3. Each survey team member conducted a pilot interview with four separate individuals who had a SCI while the other three observed and recorded answers to the questions. Each interview was critiqued so as to obtain a common method of administration. At the end of each pilot interview, the participant was asked if there were any questions that were difficult to understand or offensive. The pilot data were entered into a spreadsheet. Refinements were made to the interview, data entry and proposed analysis based on the results of this pilot work.

On completion of the pilot testing phase, it was decided that only one of the four survey team members would conduct the interview. The other three survey team members would have insufficient time to perform the interviews and would be involved only in the phone calls to invite participation into the study. If the individual agreed to participate, the appointed interviewer would then be informed to make arrangements for the interview, whether by telephone or in-person. The interviewer was also responsible for data entry.

DATA MANAGEMENT AND STATISTICAL ANALYSIS

The data from the interviews were entered into a password-protected computerized database for analysis. The data were coded and not linked to subject identifiers. Access to the database was restricted to the principal researcher and the primary interviewer (JT). Hard copies of the questionnaires were stored within TTSH-RC with access only by the survey team involved in data collection. Statistical analyses were performed with Microsoft Office Excel 2007.

The demographic information constituted categorical data and is reported as frequencies. The mean time since injury (with standard deviations) is reported and frequencies are reported for type of injury and cause of injury. Individuals were categorized as having hypertension or diabetes if they answered positively to having been told by a doctor that they had either of those diagnoses and reported taking medication for the condition. Prevalence for each chronic condition and secondary impairment was calculated. In addition, the number of secondary impairments experienced by each participant was summed and the mean number for the sample calculated.

The prevalence of participation in moderate to intense physical activity as part of their work was calculated as a percentage of the study sample. The prevalence of participation in sports or exercise was also calculated. The prevalence, frequency and reasons for smoking are reported as well as the prevalence of excess alcohol consumption. Mean CHART scores with standard deviations were calculated for each of the six

dimensions. Individual scores for each SWLS statement were summed and the mean of the total score reported.

The study sample was stratified according to time since injury (less than 5 years vs. 5 years and greater), type of injury (paraplegia vs. tetraplegia), presence or absence of a full-time paid carer and engagement in regular exercise. Non-parametric statistical tests were used due to non-normal distribution of scores. Differences in the means of CHART and SWLS scores were determined by a two-tailed Mann Whitney U Test. Spearman correlation analyses were performed to examine the relationship between CHART and SWLS scores. Chi-square tests were used to examine the influence of a full-time paid carer on the performance of leisure sports or exercise and the relationship between the latter and the number of SCI-related secondary impairments experienced. A probability value of $p < 0.05$ was considered statistically significant.

Finally, our questionnaire findings were examined with respect to the variables and their meaningfulness for establishing the variables within a database that could be used over time to track the health and well-being of people with SCIs living in Singapore. The findings were also examined as a basis for preliminary recommendations for social services and health care provision.

RESULTS

The study had a total of 55 participants. Of the sampling pool of 260 individuals extracted from the NHG database, 28 had passed away, 26 were non-residents of Singapore, 26 did not have a SCI from traumatic cause, one had cognitive problems preventing participation and 76 could not be contacted due to a change in contact number or no response when the initial calls were made. Twenty-one individuals were not fluent in English and did not have a proxy willing and able to complete the interview on their behalf. Of the remaining 82 individuals, 27 declined participation. Thus the response rate for this study was 67.1% of those with verified phone numbers and meeting the inclusion criteria. Nineteen interviews were performed in person, while the remainder was performed over the telephone. Seven interviews were conducted by proxy. Of these, four of the proxies lived with the participants.

DEMOGRAPHICS

The demographic information of the study sample is summarized in Table 1. Of the 55 participants, 50 were men and five women. Most of the participants were Chinese (83.6%). The remainder (16.4%) was Malay. On average, the participants were 48.3 (± 16.54) years old. Half of the participants (50.9%) were married and one-third (32.7%) had never married. The remainder was either divorced or widowed. The highest level of education for the majority of the participants was at the secondary level (43.6%), followed by 36.3% who had tertiary level education. The remaining participants had primary level or no formal education.

Three quarters (74.5%) of the study sample were unemployed. Of these, 87.8% reported being unable to work due to their disabilities. Thirteen percent of the participants had paid work in areas such as product design, engineering and sales. The remaining participants were either retired or studying.

The majority (80.0%) of the study sample lived in public housing apartments, of which the most common type was three to five-room apartments. Eleven percent lived in private housing (semi-detached or detached houses and private apartments or condominiums). The remainder lived in nursing homes (n=5). Besides the nursing home residents and one participant who lived alone, 89% of the study sample lived with their families. About half of the study sample (52.7%) had full-time, paid, live-in carers. Of these, 25 (of 29) required the carer to help with personal care activities.

Participants with paraplegia were younger than those with tetraplegia (38.0 y vs. 51.1 y; $p=0.005$). A larger proportion of those with paraplegia were not married compared with those with tetraplegia ($p=0.018$). The mean age of the study sample was less than the group of individuals who were not able to be contacted or declined participation in the study ($p=0.026$) (Table 2). No other differences in demographic variables were observed between groups.

INJURY INFORMATION

The most common cause of traumatic SCI in this sample was road traffic accident (52.7%, n=29). Fifteen percent (n=8) of the sample had a work-related SCI. The rest of sample (32.7%, n=18) experienced a SCI from other causes, the most commonly falls. On average, the participants had been injured for 5 years (62.5 ± 35.46 months). Forty-three participants had experienced a cervical injury, eight had a thoracic level injury and four were injured at the lumbosacral region of the spine. Thus, 78.2% were categorized as having tetraplegia (37 incomplete and 6 complete), while 21.8% had paraplegia (8 incomplete and 4 complete). Individuals were considered having complete injuries if they reported they were unable to feel or move any muscles below the level of their injuries. The main mode of mobility for most study participants was a manual wheelchair (69.1%, n=38). Only two participants used a power wheelchair. The remainder of the study participants ambulated with (n=3) or without (n=12) walking aids.

Differences were observed in the type of injury ($p=0.001$) and time since injury ($p=0.010$) between the study sample and the group of individuals who were not able to be contacted or declined participation in the study (Table 2).

SPINAL CORD INJURY-RELATED SECONDARY IMPAIRMENTS

Of the 13 SCI-related secondary impairments, spasms (67%, n=37), pain (64%, n=35), bowel problems (51%, n=28), bladder problems (47%, n=26) and edema (33%, n=18) were the most commonly reported by the participants within the 12 months preceding the study. The mean and median number of secondary impairments were 3.75 and 4, respectively.

PHYSICAL ACTIVITY

In the physical activity section of the questionnaire, work was defined as activities that the individual had to do, whether paid or unpaid. Work included activities such as household chores and looking for a job. Only two participants were involved in vigorous work and five reported being involved in moderate intensity activity as part of their work.

Twenty-four (43.6%) participants walked or propelled their wheelchairs for a minimum of ten minutes, at least three days a week. On average, they spent a little over an hour (67.8 ± 49.59 minutes) each day they walked or propelled their wheelchairs. Fifty-eight percent (n=32) of the participants reported being involved in leisure time sport, exercise, walking or propelling their wheelchairs in the preceding 3 months. Of these, half reported being involved in moderate to vigorous-intensity aerobic exercises such as swimming, cycling or walking. Fourteen (25.5%) participants reported performing regular exercise and 4 (7.3%) reported performing occasional exercise. The most common reason reported for not being involved in leisure physical activity was physical limitation. The classification for leisure time physical activity (Table 3) was adapted from the American

College of Sports Medicine's classification.¹¹¹ Table 4 shows how the prevalence of regular exercise in the study sample compared with Singapore residents, based on 2007 data.

SMOKING

Thirty-two study participants reported smoking cigarettes at some point in their lives. Of these, 21 had quit smoking completely. The most common reason given by the participants who continued to smoke daily (n=7, 12.7%), was that smoking is a habit. These individuals smoked an average of 9.3 ± 4.96 cigarettes a day. Table 4 shows how the prevalence of daily smoking in the study sample compares against that of Singapore residents in 2007.

ALCOHOL CONSUMPTION

The frequency of alcohol consumption in the 12 months preceding the study was classified as outlined in Table 5.¹¹¹ Sixteen participants (29.1%) reported consuming alcohol in the preceding 12 months. Though most (n=12) of the 16 were occasional drinkers, the prevalence of regular alcohol consumption was 3.6% (n=2). The latter was three times that reported for Singapore residents in 2007 (Table 4). On average, the 16 participants consumed 2.3 ± 1.58 drinks at a single sitting. With binge drinking defined as consuming 5 drinks or more in any one drinking session, three participants (5.5%) had binge drunk at least once in the preceding month. The prevalence of binge drinking was also higher in the study sample compared with Singapore residents in 2007 (Table 4).

SLEEP AND STRESS

On average, participants slept 7.2 ± 1.73 hours a night. One-third of the participants (n=18) reported sleeping soundly. Seventy-one percent (n=39) reported moderate to high stress levels. Many participants found difficulty identifying the area of their lives which had to change to reduce their stress. Physical health status was the most frequently (n=14) reported area of life that needed to change in order to reduce stress, followed by employment (n=7).

DIABETES MELLITUS

Seven participants were told by their doctors at some point that they had diabetes. The prevalence of diabetes was 9.1% with five participants being told by a doctor that they had the condition and also currently on medication for it. On average, they had had diabetes for 11.4 ± 10.90 years. Four participants were taking oral hypoglycemic agents. One participant was having both insulin injections and taking oral medication. When asked what they did to control their diabetes, the most common response was to reduce sugar intake. Most of the participants with diabetes sought treatment at a specialist outpatient clinic (80%) a mean of more than six (6.25) times in the preceding 12 months.

HYPERTENSION

Seven participants were told by their doctors that they had hypertension. Of these, 6 reported taking medication to control their blood pressure. Thus, the prevalence of hypertension was 10.9%. The average number of years these participants had been diagnosed with hypertension was 12.2 ± 8.95 . Four of the six participants who had hypertension also had diabetes. The most common way participants chose to control their hypertension was to reduce fat intake, followed by reducing salt intake and losing weight. Most of the participants with hypertension sought treatment at a specialist outpatient clinic (66.7%) a mean of six times in the preceding 12 months.

OTHER CHRONIC CONDITIONS

Participants were asked if they had ever been told by a doctor if they had any of the following health conditions: chest pain due to heart problems, heart attack, stroke, arthritis, asthma, high blood cholesterol or lipids, overweight or need to lose weight, cancer and smoking-related condition such as emphysema. Almost a quarter of the participants reported being told they were overweight (23.6%, n=13) and/or had high blood cholesterol (21.8%, n=12). The next most frequently reported conditions were asthma and arthritis (7.3%, n=4 each). Table 6 shows how the prevalence of diabetes, hypertension, high cholesterol and asthma in the study sample compared with that for Singapore residents based on the National Health Surveillance Survey Report in 2007.¹¹¹

MEDICAL AND HOSPITAL UTILIZATION

Thirteen participants (24%) reported visiting a private general medical practitioner or a government polyclinic in the preceding 3 months for a medical condition. Reasons for doing so varied and included the flu, pressure sores, urinary tract infections and falls. Sixty-five percent (n=36) of the sample had visited at least one specialist within 3 months of the interview. The most frequently seen specialist was the rehabilitation physician (n=26), followed by the urologist (n=8).

Nineteen participants (35%) had been hospitalized in the 12 months preceding this study. The reasons for hospitalizations included urinary tract infections (n=3), kidney or bladder stones (n=2), stroke (n=2) and pressure sores (n=2). The average length of stay in hospital was 15.5 ± 21.68 days.

PARTICIPATION – CRAIG HOSPITAL ASSESSMENT AND REPORTING TECHNIQUE (CHART)

Five participants did not complete the entire CHART questionnaire as they were living in nursing homes which made many questions in the CHART not applicable to these participants. The 'physical independence' section of the CHART had an additional five sets of missing data as participants were unable to provide answers for one or more of the questions in that section. The 'economic self-sufficiency' section of the CHART was scored for only 23 participants, also due to missing data. Table 7 shows the means and standard deviations for each section of the CHART. The highest scoring section was 'cognitive independence' and the scores for 'occupation' were the lowest. The highest possible score on each section was 100.

GENERAL LIFE SATISFACTION – SATISFACTION WITH LIFE SCALE (SWLS)

The SWLS was completed by 46 participants. Of those who did not complete the SWLS, seven were proxies and two participants were unable to understand the questions. The mean SWLS score was 13.9 ± 9.48 out of a possible maximum score of 35.

BETWEEN GROUP COMPARISONS OF MEAN CHART AND SWLS SCORES

Fifty-three percent (n=29) of the sample had had their SCIs for five years or more. No differences were observed for the mean CHART scores ($0.144 \leq p \leq 0.726$) or SWLS scores ($p=0.933$) between participants who had had their SCIs for more than or equal to 5 years and fewer than 5 years.

Participants with paraplegia (n=11) had higher mean scores (94.8 vs. 82.8; $p=0.022$) on the 'physical independence' section of the CHART than those with tetraplegia (n=34). There were no differences in the mean total SWLS scores ($p=0.077$) and CHART scores ($0.072 \leq p \leq 0.991$) in the other five sections based on type of injury.

Participants who had a full-time, paid, live-in carer had lower mean scores on the 'physical independence' (76.5 vs. 97.2; $p<0.0001$), 'cognitive independence' (84.0 vs. 94.6; $p=0.043$) and 'mobility' (49.3 vs. 76.0; $p=0.001$) sections of the CHART than those who did not. There were no differences observed for the mean total SWLS score ($p=0.600$) and the other three CHART scores ($0.051 \leq p \leq 0.954$) between those who had full-time, paid, live-in carers and those who did not.

Participants who reported engaging in regular exercise had higher mean scores on the 'occupation' (48.5 vs. 25.8; $p=0.021$) and 'social interaction' (87.3 vs. 63.6; $p=0.006$) dimensions of the CHART than those who did not. There were no differences observed for the mean total SWLS score ($p=0.831$) and the other four CHART scores ($0.081 \leq p \leq 1.00$) between those who reported engaging in regular exercise and those who did not.

Table 8 and 9 show the mean CHART and SWLS for the different groups.

CORRELATION BETWEEN CHART SCORES AND TOTAL SWLS SCORE

The Spearman rho for the association between 'Cognitive Independence' and SWLS scores was 0.338 ($p=0.017$). There were no associations observed between the remaining five CHART dimensions and SWLS (Table 10).

INFLUENCE OF FULL-TIME, LIVE-IN CARER ON LEISURE PHYSICAL ACTIVITY

There was no difference ($p=0.633$) in the prevalence of participants who were involved in leisure physical activity (sports, exercise, walking or propelling their wheelchairs) between those who had a full-time, paid, live-in carer and those who did not.

INFLUENCE OF PHYSICAL ACTIVITY ON SCI-RELATED SECONDARY IMPAIRMENTS

The sample was stratified into those who had more than three and three or fewer SCI-related secondary impairments for the Chi-squared analysis. No relationship ($p=0.803$) was observed between involvement in leisure physical activity and the number of SCI-related secondary impairments reported.

DISCUSSION

This study provides a cross-sectional overview of the health of people living with SCI in Singapore. Our findings support the need for a formal database to help refine health services provision over their life cycle, with a view to optimize quality of life and reduce the social and economic burdens of SCI in Singapore.

DEMOGRAPHICS AND INJURY INFORMATION

There were no Singaporeans of Indian ethnicity included in this study, which is not representative of the general Singapore population of which 74% are Chinese, 13% Malay and 9.2% Indian.¹¹¹ The median age of the sample was older than the general Singapore population (51 y vs. 37 y). This difference may be more pronounced in actuality since the mean age of the study sample is lower than the potential participants who were not contactable or declined participation. This may reflect the aging population and high level of acute and sub-acute medical care in Singapore, as well as, support the evidence that increasing age is associated with increasing disability.¹¹² A smaller proportion of the sample was currently married than the general Singapore population (50.9% vs. 60.7%) and a greater proportion, divorced (7.3% vs. 3%) or widowed (9.1% vs. 5%). However, the mean household size of this sample was greater than that of the general Singapore population (4.0 vs. 3.5 people). This may be an important reflection of the type of family support that people with SCI have.

Consistent with the epidemiology of SCI in other countries,³⁴ trauma was the main cause of SCI in Singapore. After road traffic accidents, falls were the next most common

cause of injury. Together with the older age of this sample, these results support the evidence showing a trend of increasing frequency of falls as a cause of SCI together with increasing mean age at time of injury.^{30, 35} Though consistent with reports that more men than women acquire SCI, the ratio of men to women in this study (10:1) is greater than reported elsewhere.^{29, 35, 113} People with tetraplegia were also overrepresented in our sample. Considering the study sample together with the potential participants who were not contactable or declined participation, the prevalence of tetraplegia and paraplegia would be 60.9% and 39.1% respectively; the prevalence of tetraplegia still being higher but closer to that in Canada (46% in 1999)³⁴ and the United States (52.4%).³²

The main mode of mobility for our sample was a manual wheelchair (69.1%). Only two participants used a motorized wheelchair. This information is important when considered together with the high proportion of people with tetraplegia in the sample. This may reflect practice norms in Singapore with regard to the prescription of motorized wheelchairs. Most customized wheelchairs are imported into Singapore which increases their cost.¹¹⁴ In the case of motorized wheelchairs, these are more expensive than manual ones. Financial limitations may be a critical factor in deciding the type of wheelchair prescribed by the rehabilitation professional (most often, the occupational therapist) for the individual with SCI. The rate of private insurance is low in Singapore. Most people are reliant on government-controlled medical savings accounts^{25, 115} to pay for medical expenses. Although some government or hospital-based funding for assistive technology is available, people with SCI and other disabilities must meet strict funding guidelines for

funds to be released. These guidelines are largely based on the individual's household income per capita¹¹⁶ and not necessarily the severity of injury.

Another reason for the low prevalence of motorized wheelchair use in Singapore could be the physical environment. Though much has been accomplished in the last decade to create a barrier-free environment,¹¹⁴ mobility in public places may be hazardous for wheelchair users. For example, curb cuts are not consistently available at all street corners and crossings. The availability of elevators at all entrances to mass rapid transit (MRT) stations is also inconsistent. Access in and out of the home is also often a problem for those who have steps leading up to the main door. Though there are no studies to confirm this, rehabilitation professionals may not be confident that a motorized wheelchair would improve the mobility of their clients in and around the home. This uncertainty coupled with the need to prioritize equipment purchase based on limited financial options may limit the prescription of the equipment.

Studies that examine the clinical reasoning process of rehabilitation professionals in wheelchair prescription – manual and motorized – would be beneficial. This would provide insight into the reasons for the apparently low use of motorized wheelchairs and justification for greater funding if indeed financial factors play the largest role. Research on the effect of motorized wheelchair use on participation levels and the ease of use of motorized versus manual wheelchairs in Singapore would also provide valuable information for rehabilitation professionals involved in wheelchair prescription.

SPINAL CORD INJURY-RELATED SECONDARY IMPAIRMENTS

The top five reported SCI-related secondary impairments were spasms, pain, bowel problems, bladder problems and edema. Pressure sores were also common with almost a quarter of the participants reporting them. This list corresponds to the results obtained by Bloemen-Vrencken et al^{45, 49} in the Netherlands although the order and prevalence differ. Bloemen-Vrencken et al⁴⁵ also asked participants about the importance of the reported secondary impairments and their impact on their social lives and daily activities. Participants reported spasms, pain, bladder and bowel problems and pressure sores to be the most important. Pain and spasms had the greatest impact on daily activities while bladder and bowel problems affected social life more than daily activities. Another study reported that dependent individuals with SCI with bladder and bowel problems had lower levels of life satisfaction and may have problems creating new social relationships.¹¹⁷ Tonack et al⁹⁴ also reported that people with SCI who were experiencing moderate to severe chronic pain had less life satisfaction and lower participation.

From this study, less than half of the participants reported visiting a rehabilitation physician in the year preceding the study. The high prevalence of secondary impairments and the known negative impact of them on health, participation, life satisfaction and mortality⁴⁶⁻⁴⁸ support the need for periodic monitoring of these conditions over the lifetime of individuals with SCI. Family physicians of people with SCI would benefit from receiving education about additional questions¹¹⁸ that need to be asked during regular health screenings in this population. For example, questions about bladder and bowel control,

blood pressure control, skin integrity, pain, spasticity, equipment needs, changes in strength, impaired sensation and impaired functional ability are key SCI-specific concerns warranting ongoing evaluation.

CHRONIC CONDITIONS AND ASSOCIATED RISK FACTORS

The results of this study support the evidence that individuals with SCI are more likely than the general population to experience a constellation of chronic conditions such as diabetes, hypertension, obesity and high cholesterol levels, all of which increase the risk of cardiovascular disease.⁵² When compared to Singapore residents in 2007,¹¹¹ our study sample had a higher prevalence of diabetes, high cholesterol and asthma. The prevalences of hypertension and diabetes were identical when only participants from age 21 to 69 years were considered.

Although we could not make direct comparisons, our results suggest that the proportion of people with SCI who are overweight and obese may be greater than the general population in Singapore. This is consistent with the current data on the prevalence of obesity in people with SCI even though current data may be underestimated.⁵⁷ The 2007 National Health Surveillance Survey¹¹¹ reported the prevalence of obesity in Singapore residents as 5.7% based on BMI calculated from self-reported height and weight. The proportion of participants who reported being told they were overweight in this study was 23.6%. This number is concerning given obesity is associated with and is an independent risk factor¹¹⁹ for several comorbidities such as congestive heart failure, diabetes, pressure

sores and depression. Obesity has been reputed to mediate the increasingly prevalent 'metabolic syndrome' in this population.⁵⁷

Behavioral risk factors for chronic conditions such as smoking,⁶¹ physical inactivity⁵⁸ and excessive alcohol consumption⁶⁰ are also cause for concern among people with SCI. The results of this study confirm this with higher reported prevalences of binge drinking and daily smoking than the general population. Although over half of the participants reported being involved in leisure time sports, exercise, walking or propelling their wheelchairs, the prevalence of reported regular physical activity among the study sample was only slightly higher than for the general population. This suggests that much of the leisure time physical activity that participants engaged in was not necessarily sufficiently intense, long or frequent to produce physical health benefits. The combination of higher prevalences of chronic conditions and their associated risk factors highlight the need for increased preventive care services for this population.¹²⁰

Regular physical activity has been associated with positive benefits for weight management, and the control of glucose and blood pressure as well as lipoprotein profiles.⁵² Physical activity also has the potential to exert a protective effect on SCI-related secondary conditions such as pressure sores.⁶³ The unique physical and metabolic factors that need to be considered for exercise prescription in individuals with SCI build a strong case for the involvement of physical therapists in the care of individuals with SCI after discharge from inpatient rehabilitation. Physical therapists need to be highly knowledgeable about the unique effects of SCI on the neurologic, cardiovascular and

musculoskeletal systems during exercise. The appropriate exercise mode, duration, intensity and monitoring can then be prescribed for optimal effectiveness and with considerations for safety. Education about exercise prescription in patients with SCI should be conducted for physical therapists working in organizations servicing people with SCI in Singapore.

The American College of Sports Medicine¹²¹ recommends that SCI exercise programming includes a variety of cardiopulmonary exercises to prevent overuse of the arms and ensure strengthening of muscle groups requisite for activity. Exercise options are limited for people with physical disabilities in Singapore. Sport for people with disabilities is in its infancy and has not been integrated into rehabilitation programs. Physical therapists could play a role in initiating and developing collaborative partnerships between hospital rehabilitation units and organizations such as the Singapore Disability Sports Council (SDSC). Programs could be developed to introduce newly injured patients to the variety of disability sports available. Physical therapists have expert knowledge on the influence of neurological impairments on exercise capacity. Their role could be to assess the fitness of clients for participation in sport and provide consultation to organizations like SDSC which have specialized knowledge of and logistical support for the individual sports.

Besides the physical health benefits of exercise, leisure time physical activity also has psychosocial benefits and a positive influence on life satisfaction.^{122, 123} The results of our study support this. The 'social integration' scores were higher for participants who reported regular physical activity than for those who did not. Exercise, especially group

sport, brings people together, thus provides a natural platform for peer support among people with similar disabilities. Exercise may not only prevent disease but also contributes to the overall health of individuals with disabilities such as SCI. Resources to create opportunities enable people with SCI and other physical disabilities to participate in exercise would be cost efficient.

The lack of differences in CHART scores for the 'physical independence', 'cognitive independence' and 'mobility' between study participants who participated in regular physical activity and those who did not, suggests that involvement in physical activity may not have been as dependent on physical limitations as may be assumed and reported elsewhere.⁵⁸ Kinne et al¹²⁴ support this argument in a study that observed motivation and self-efficacy to be greater barriers to exercise than disability characteristics. Further, Skelza and colleagues reported that people with SCI perceive many environmental barriers to exercise.¹²⁵ These include lack of accessibility, inexperience of fitness center staff to meet the needs of people with disabilities, scost of the exercise program and not knowing where to exercise.

Many of the barriers reported¹²⁵ are likely applicable in the Singapore context. The work of removing physical and attitudinal barriers in Singaporean society needs to continue so that people with SCI and others with physical limitations have equal access to fitness and recreation facilities. Measures that directly influence motivation and self-efficacy need to be examined also. Physical therapists could provide education and training to personal trainers in private gyms with respect to assisting people with SCI to use the gym

equipment. The physical therapy department of one hospital, i.e., Tan Tock Seng Hospital has developed partnerships with some of the fitness gyms operated by the Singapore Sports Council. A program facilitating the transition of patients from the hospital knee exercise classes to performing their exercises independently in the fitness gyms has been developed. A similar program could be developed for people with SCI. This may help increase their self-efficacy in performing regular exercise independently in the community.

Addressing smoking cessation and excess alcohol consumption in people with SCI are additional areas that warrant focused attention. As in the general population, both of these lifestyle behaviors contribute to increased morbidity and mortality and lower quality of life^{54, 62, 64, 126} in people with SCI. Despite the recognition that smoking is a primary risk factor for many chronic conditions,¹²⁷ the practice of implementing smoking cessation strategies is low among health professionals including physical therapists. A recent systematic review supports the use of advice by physical therapists as an evidence-informed smoking cessation strategy.¹²⁸ Physical therapists need to develop competencies in the administration of smoking cessation advice as well as in areas such excessive alcohol consumption.¹²⁹ They would also benefit from knowing when and how to collaborate with physicians and other health professionals like psychologists to address these issues given the likelihood of smoking cessation increases when addressed by more than one health professional over time.¹³⁰ A combination of smoking cessation strategies is ideal.¹³¹

These competencies are especially necessary for physical therapists who work with people with SCI and other disabilities in which smoking, excessive alcohol consumption and

the chronic conditions with which they are associated with are more prevalent.^{55, 60, 132, 133} A recent study among general practitioners, pharmacists, nurses, dentists, dental hygienists and respiratory therapists reported that the belief that smoking cessation counseling is the role of health professionals, perceived self-efficacy to engage in effective smoking cessation counseling, and knowledge of community cessation resources were positively associated with smoking cessation counseling practices.¹³⁴ Interventions addressing these factors in physical therapists may also help increase smoking cessation counseling practice within the profession.

Another overlooked contributor to health is sufficient sleep. Sleep deprivation has been shown to have a negative impact on function and well-being¹³⁵ and is a risk factor for chronic conditions such as heart disease.¹³⁶ In our study, participants reported sleeping a similar number of hours per night on average as a young adult in the general population (7.5 hours). However, only a third of the participants slept soundly. Studies concur however that the average human may actually require 9.5 to 10 hours of sleep every 24 hours.¹³⁵ Coren's¹³⁵ review of sleep health and its relation to physical therapy practice recommends that physical therapists be equipped with skills in the assessment and basic management of sleep disturbances. Our study did not pursue the reasons for poor sleep, but questions about sleep health would be interesting to include in future studies as well as in clinical practice. A large proportion of participants reported experiencing pain, spasms and bladder and bowel problems. It could be hypothesized that these secondary impairments influence the ability of individuals to either fall or stay asleep. Treatment of

these secondary impairments may have direct influence on the quality of sleep and thus the overall health of the individual.

Sleep and stress also have been shown to be associated.¹³⁶ One study has reported that stressful life events are associated with sleep duration and fragmentation.¹³⁷ The acquisition of a SCI would be considered a stressful life event. The majority of the study sample reported moderate to high stress in their daily lives. Whether or not sleep disturbance and stress levels are related in our sample is unknown. However, the prevalence of both problems contributes further to the complexities surrounding the health of individuals with SCI.

Physical therapists involved in the care of clients with SCI need to be aware of the numerous multisystem and psychosocial effects of SCI and their interactions with each other. Competencies in assessing and managing different contributing factors would help provide holistic care by physical therapists. Physical therapists' role as health educators is critical among people with SCI given the increased vulnerability of this population. The nature of physical therapy provides an opportunity to influence the health of our clients given client-therapist relationships are often long term. Physical activity and exercise, the mainstays of the physical therapy profession, have wide ranging benefits on health, including sleep and stress. Thus it is imperative that physical therapists in Singapore maximize their strategic position in the healthcare system, to influence the health of people with SCI, other disabilities and the general population as a whole.

MEDICAL AND HOSPITAL UTILIZATION

Participants in the 2007 National Health Survey¹¹¹ were asked if they had seen a medical general practitioner (GP) or gone to a government polyclinic in the preceding 12 months. This study required participants only to report on GP or government polyclinic visits in the preceding three months. The results are thus not directly comparable. There is however dissimilarity in the results in that almost all the participants in the 2007 National Health Survey¹¹¹ sought treatment for chronic conditions (i.e., diabetes, hypertension, and high blood cholesterol) from either a GP or a polyclinic doctor, while participants in this study mostly sought treatment for chronic conditions (i.e., diabetes and hypertension) from a specialist, usually the rehabilitation specialist. The sustainability of this greater reliance on specialist treatment for chronic conditions may be cause for concern. It would be interesting for future studies to determine how long an individual continues to have consultations with the rehabilitation specialist, and the criteria used in the decision. With limited healthcare resources, the need for specialist care should be sufficiently justified.

PARTICIPATION

The results of our study indicated that people with traumatic SCI in Singapore have lower levels of participation than people with SCI in the United States and England⁶⁶ where the CHART has been used extensively to monitor long-term participation this population. The CHART scores obtained in our study were also lower than that obtained in a Japanese population with SCI.¹³⁸ The differences in CHART scores were observed in every dimension, with the greatest difference observed in the 'occupation' dimension. The low CHART

scores were not unexpected. However, the interview process highlighted certain social and cultural norms in Singapore that must be considered in the interpretation of these results.

The high prevalence of full-time, live-in carers is one of the factors that may have affected the answers to questions in the 'physical independence' and 'cognitive independence' dimensions of the CHART. The first question in the 'physical independence' dimension asked how many hours participants have somebody present to assist them with personal care activities. Many participants who had full-time, live-in carers would initially respond with '24 hours'. When asked to focus only on the time that the carer spent on personal care activities, some participants reported durations that were suspected to be shorter than they actually were, which would have resulted in an overestimation of their physical independence. If '24 hours' was the answer used to compute the 'physical independence' score, participants with a full-time, live-in carer would not be able score above 28, which would probably underestimate their physical abilities.

Our study excluded individuals who had cognitive impairments which would affect their ability to receive, process and express information. Thus, higher scores were expected than those observed in the 'cognitive independence' dimension. The lower than expected scores could also be due to having a full-time, live-in carer. The first two questions in the 'cognitive independence' dimension that asked about the amount of time the participant had someone present (within or without the home) to assist in remembering, decision making and judgment. The participant had to answer from a list of possible options, that were phrased in such a way that may have led participants to choose

a lower scoring answer more because their carers were always present with them in and out of home, than because they were less involved or had less ability in remembering, decision-making and judgment.

In addition, the final question in the 'cognitive independence' section asked about the amount of control the participant had over his or her money. It is common in the Singapore cultural context for decisions to be made in consultation with other family members.^{139, 140} If an individual has a disability, is unemployed and financially dependent on his or her family, it would not be uncommon for the majority of financial decisions to be relinquished to the family.¹⁴¹ The fact that less than half the participants were able to provide answers to both questions in the 'economic independence' dimension may be support for this hypothesis. Many of the participants did not know how much their annual household income was or their annual medical expenditure. There would be much variability in these situations, but this could be a contributing factor to the lower than expected 'cognitive independence' scores. The scores should not be interpreted too negatively.

Low mobility scores could have been influenced by the low use of motorized wheelchairs. The use of a manual wheelchair would increase the likelihood of assistance being required since the individual would likely fatigue more quickly. Advanced wheelchair skills are needed for an individual to be independent in mobilizing in a manual wheelchair. This would be more challenging for individuals with tetraplegia than paraplegia. Given the

former comprises a greater proportion of our study sample, the low scores on the 'mobility' dimension may be accounted for.

Having a full-time, live-in care on 'occupation' scores could have been expected to positively influence scores in the 'occupation' dimension of the CHART. It may be hypothesized that having full-time assistance with personal care activities and mobility could encourage the individual to be more involved in a variety of activities since the carer is present throughout the day to provide assistance with mobility. However our results were in the opposite direction; those who did not have full-time, live-in carers having higher 'occupation' scores. In addition, there was also no observed difference in the number of people who participated in leisure time physical activities between those who had a full-time, live-in carer and those who did not. Participants with full-time, live-in carers were more physically and cognitively dependent than those without and this may explain the lower 'occupation' scores. Do these results imply that the role of the carers is merely to assist in personal care and other basic activities of daily living (ADLs)? In Singapore, full-time, live-in carers of people with disabilities are also expected to perform other household duties that may not be directly related to the care of the individual whom she was employed to mainly provide care for. The carer may even be caring for more than one person. This may limit the actual amount of time that the carer has to directly assist the individual with activities not perceived as urgent or important (e.g., leisure or self-improvement activities). The person with a disability may also not feel empowered to request assistance in the latter if he or she is not financing the carer.

These results should stimulate thought among rehabilitation professionals about the education that clients and their families are receiving on the role of a full-time, live-in carer. By only involving and training carers to assist with personal care activities and basic ADLs, rehabilitation professionals may be communicating and reinforcing the perspective that the carer is only to assist with those tasks. In addition to assisting with ADLs within the home, carers should also be skilled and confident in assisting the client with mobility in public places (e.g., food courts and shopping malls), on public transport and in leisure activities, such as sport or exercise. Not only do the carers need to be confident in the physical skills required to assist clients, but the client needs to be confident in giving instructions to his or her carer. Sufficient time needs to be given within the inpatient rehabilitation setting for an optimal working relationship and effective communication between the client and his or her carer. Pressure to shorten lengths of stay in the hospital may not allow for this. The relative ease and affordability of obtaining a full-time, live-in carer in Singapore needs to be maximized, to allow increased participation of people with SCI and other disabilities in various life situations.

In the measurement of 'occupation', watching television and listening to the radio were not considered under recreation or self-improvement activities. This is because only activities that society considered as valuable in fulfilling social roles were included in the design of the CHART.⁴ The CHART was designed based on social norms for people without disabilities in the United States. It is unknown whether or not Singaporeans place the same social value on different activities as Americans. In this case, if Singaporeans who do not have physical disabilities view watching television and listening to the radio as socially

valuable means of recreation and self-improvement, it would be necessary for time allocated to these activities to be included in the CHART. For example, another activity that may be valued differently by Singaporeans and Americans may be home maintenance activities. Like most Singaporeans, most participants in our study live in apartments, thus, home maintenance activities are less of a priority than if they lived in houses.

Another assumption of the CHART is the social desirability of a person being independent. This is especially evident in the 'physical independence', 'cognitive independence' and 'mobility' dimensions where many of the questions emphasize tasks being done without assistance. The CHART thus was not merely measuring the extent to which an individual with a SCI was involved in the six dimensions of life, but the extent to which he or she is involved with those life situations independently. Although it is typical for people to accomplish most tasks in life independently, participation in life situations cannot be said to be restricted merely because assistance is required. This may explain why an individual's perception of the quality and method of participation (subjective participation) has become a focus of attention in the field. Objective measures like the CHART provide valuable but limited information about the complex construct of participation. In Singapore, foreign, full-time, live-in helpers are common and participate in many aspects of daily living (e.g., household chores and child care) for people without disabilities as well as for those with disabilities. Thus for a person with a physical disability, if a task can be completed competently with the assistance of a full-time, live-in carer, he or she may not perceive involvement in that dimension of life to be restricted, thus, should

not be considered so. Measures of subjective participation have been developed and have attempted to elucidate such information.

Hansen et al¹⁴² piloted the Perceived Handicap Questionnaire (PHQ) to assess perceived success in five ('cognitive independence' not included) domains of the CHART among 78 individuals with traumatic SCI. Cardol et al⁷⁰ developed the Impact on Participation and Autonomy Questionnaire (IPAQ) to measure perceived participation and perceived problems in five life domains. The Assessment of Life Habits (Life-H) measures the difficulty and the amount of assistance required with a task and the individual's satisfaction with the performance of that task.⁶⁸ The measurement of subjective participation can provide a more complete picture of the involvement of an individual in life situations. The inclusion of such measures in studies on the participation of people with SCI and other disabilities conducted in Singapore would be beneficial.

To our knowledge, our study constitutes the first use of the CHART in a target group in Singapore. The social and cultural norms that may have affected our results warrant further examination to determine the appropriateness of the CHART for use in Singapore. Reference data on the participation of people without disabilities in the country would constitute an advance for the objective comparison of participation between populations in Singapore and cross culturally.

GENERAL LIFE SATISFACTION

The use of the SWLS shed light on the quality of life of people with SCI in Singapore. Although people with SCI tend to score lower than the general population on measures of quality of life, including life satisfaction, the differences appear small and not significant.¹⁴³ The mean SWLS score observed in this study however, was lower than that reported in studies of people with SCI living in North America by several points.^{90, 94, 144} The relative low scores we observed may be explained in part by cultural differences between Singaporeans and North Americans.

Cross-cultural studies consistently show that people with Eastern cultural heritage report less frequent and intense positive affect and lower life satisfaction than people with a Western cultural heritage. However, the actual frequency and intensity of experiences of positive and negative emotions are similar.¹⁴⁵ Wirtz et al¹⁴⁶ provided insight into this observation in a series of three studies. The studies showed that Asian Americans and Japanese paid more attention to and relied more on negative affect in judging their satisfaction with a vacation, friendship and life. This is in contrast to European Americans who placed more emphasis and meaning on positive affect. In general, East Asians tend to focus on the negative aspects of experiences potentially contributing to low life satisfaction.

In addition, differences in value systems may affect the evaluation of life satisfaction. In Asian culture, for example, the value placed on the fulfillment of roles and responsibilities is higher than in the Western culture.¹⁴⁷ The inability to fulfill one's roles

and responsibilities as a result of a disability in Asian culture likely negatively influences an individual's perception of self worth and how he or she evaluates life satisfaction.

To our knowledge, there has been no other published literature on the life satisfaction of people with SCI or other physical disabilities in Singapore to date. Although cultural differences could explain the lower SWLS scores obtained in our study, these results should not be dismissed. Quality of life studies in the general population in Singapore have reported that Singaporeans are generally satisfied with life.¹⁴⁸

Kau and Hooi¹⁴⁸ reported that health was the most important factor in determining the life satisfaction of Singaporeans. Therefore, the often severe and long-term effects of a SCI on the health of the participants of our study may explain the low life satisfaction they reported. That participants reported 'physical health status' as the most common cause of moderate to high stress corroborates this view. In addition, the number of chronic conditions participants have and their SWLS scores were inversely but weakly associated.

While comparison between the results of previous studies on quality of life and the present study is not entirely possible due to differences in outcome measures, the possibility that people with SCI do have lower life satisfaction than the general population in Singapore and similar populations internationally, requires further investigation. Determining the best outcome measures constitutes an important initial area of research. The questionnaires used in the studies by Kau¹⁴⁸ and Ibrahim¹⁴⁹ examined satisfaction with life overall as well as various pre-selected domains of an individual's life. Ibrahim¹⁴⁹ also calculated an overall life satisfaction score from 18 life domains. Singaporeans may

evaluate satisfaction more easily in relation to specific areas of life. During our interviews, participants often asked which part of their lives the statements in the SWLS referred to. Even though the reliability and validity of the SWLS to measure general life satisfaction has been widely established in other nations, replication of these studies in Singapore will establish its appropriateness in this cultural context. Reference data for the SWLS will help investigators in making comparisons that are meaningful.

RELATIONSHIP BETWEEN PARTICIPATION AND LIFE SATISFACTION

The positive association that was expected between participation and life satisfaction was not demonstrated by our data. This could be due to the choice of outcome measures used for both constructs. First, given that the judgment of life satisfaction is influenced by culture, a uni-dimensional evaluation is likely insufficient. The use of multidimensional measures of life satisfaction such as the Life Satisfaction Index-A,¹⁵⁰ which measures zest for life, mood tone and congruence between desired and achieved goals, may capture better various interpretations of life satisfaction. Associations with other constructs such as participation may then lead to different results.

Second, there is evidence that subjective participation may be more critical than objective participation in determining life satisfaction. Hansen et al¹⁴² reported that perceived participation (PHQ scores) was associated with life satisfaction (Life Satisfaction Index-Z). To the contrary, CHART scores did not explain the variance in life satisfaction. Fuhrer and colleagues⁸⁷ reported a positive association among 'mobility', 'occupation' and 'social integration' dimensions of the CHART and life satisfaction (Life Satisfaction Index-A).

However, this association appeared to be mediated by 'perceived control'. Perceived participation was observed to be associated with life satisfaction in one study that used the IPAQ and the Life Satisfaction Questionnaire (LiSat-9) as outcome measures.⁹³ Schopp et al⁷⁵ observed that perceived choice in certain tasks such as bladder care and leaving home was associated with higher satisfaction in those activities. Thus, one could hypothesize that the degree of choice that an individual perceives he or she has in the subjective experience of participation influences life satisfaction.

Given the lack of information on the applicability of the various participation measures to Singaporeans, a decision was made to use the CHART and SWLS in our study. This is because the data collected from these measures was objective and would likely be more valued by health authorities than subjective measures. In addition, the CHART and SWLS had more international data available for comparison. Other tools should be explored.

Besides a weak association that was observed between the 'cognitive independence' dimension and life satisfaction, there was no association between other dimensions of the CHART and life satisfaction. These results appear to support that life satisfaction in people with SCI is more influenced by the subjective experience of involvement in life situations than the observable and quantifiable aspects of actually participating. This highlights the importance of giving voice to people with disabilities in Singapore including those with SCI. In Singapore, disability issues have been on the sidelines and relatively little effort has been invested into the unique needs of this

population. Improving the lives of those with disabilities in Singapore requires that resources are targeted at areas that are of most relevance and concern to this population. These concerns cannot be assumed by health care providers or stakeholders other than the affected individuals themselves. Resources therefore need to be allocated to research as well as to services in dialogue with the primary stakeholders, those affected by SCI. Despite the expertise of health professionals, the experiences and opinions of those living lives limited in some way by a physical or mental disability need to be valued, heard and changes implemented by health care providers and agencies based on this discourse. Systems need to be established to allow for effective flow of information between people with disabilities and health authorities. In this way, appropriate and timely measures can be instituted as indicated and eventually evaluated and modified as needed.

One factor that has been reported to influence participation and life satisfaction is a person's accessibility to the environment.⁹² A study by Richards and colleagues⁸⁸ investigated the association between one's access to the environment and life satisfaction. He reported that access to the environment (indoor and outdoor) increases life satisfaction. Since Singapore is in the early stages of creating barrier-free access for people across all sectors of society, studies on the extent to which current changes in accessibility have impacted the lives of people with disabilities in Singapore to date would help to inform future research. However, reducing environmental barriers, specifically in the physical environment, is only the beginning of facilitating full participation of individuals with disabilities in society.⁹²

SUGGESTIONS FOR THE DEVELOPMENT OF A LONGITUDINAL DATABASE

The Model SCI Systems and the National SCI Statistical Center (NSCISC)¹⁵¹ in the United States, and the Australian Spinal Cord Injury Register (ASCIR)¹⁵² are models of longitudinal databases that collect and maintain information on the etiology of SCI and the health of people with SCI in each country. The incidence of SCI may be relatively low,^{98, 153} however, the severe, chronic and costly consequences of such injury justify the development of a database to collect, maintain and monitor trends in the incidence, prevalence, etiology and management outcomes of people with SCI. As in the United States and Australia, strategies can then be identified to prevent SCI as well as meet the health needs of the existing population. In Singapore, the successful development of such a database may be a platform for collaboration between researchers and clinicians in across rehabilitation centers and related organizations in Singapore. Such collaboration could serve as a springboard for other research initiatives as networks become established.

As in the NSCISC database and ASCIR, information on the etiology of the injury and the demographic information of people who sustain a SCI need to be included in a Singapore database. Due to the relatively small population in Singapore, it may be useful and not overly time consuming to collect information on SCI due to both trauma and disease. Although not investigated in this study, measures of impairments (e.g., ASIA scores) and functional capacity (e.g., Functional Independence Measure) could serve as indicators of the severity of injury and allow for comparison of the expected and observed outcomes of SCI rehabilitation.

Long term outcomes of SCI need to be measured and monitored over time; a concept integral to outcome measurement. Outcome measures on participation should be included to provide indication on the extent of community reintegration of the population. Our study highlighted attributes of the CHART that suggest it may be less than an ideal tool to measure participation in the Singapore population. Exploration of other measures such as the Return to Normal Living Index or the Assessment of Life Habits is indicated and may result in the need to develop a unique, culturally relevant instrument for use in Singapore. In addition, knowledge of subjective participation provides a more holistic view of the participation of people with SCI. Further, it may help elucidate the associations between participation and aspects of quality of life including life satisfaction.

The construct of quality of life has become an important indicator of successful rehabilitation and community reintegration. From our study, life satisfaction may be better assessed with a multi-dimensional tool. Within the context of healthcare, health-related quality of life, and self-reported health may be beneficial measures to include in the proposed SCI database.

Finally, factors that could influence short and long term outcomes of SCI need to be included in an evolving SCI database or registry, e.g., secondary SCI impairments, and chronic conditions and their associated risk factors. Knowledge that spasms, pain and bladder and bowel problems are prevalent and can lead to serious morbidity, even mortality, supports that information about these issues warrant being followed and captured in detail. Chronic conditions and their associated risk factors were reported to be

more prevalent by the participants in our study than reported by other sources for other Singapore residents. Their prevalence was also moderately inversely associated with life satisfaction. Continued monitoring of these factors within a database would be useful to evaluate the effectiveness of efforts to translate and integrate health promotion in this population.

To reduce the burden of data collection on the investigator and individuals with SCI in studies such as ours or evolving databases thought needs to be given to the minimum dataset that would provide essential information and at which stages in the rehabilitation of an SCI they should be collected.

RECOMMENDATIONS FOR REHABILITATION PLANNING AND IMPLEMENTATION

The implications for SCI rehabilitation based on the findings of our study include the need for focused attention on the care of the individual with SCI after discharge from inpatient rehabilitation and over the long term. Systematic planning to promote community reintegration and ensure maximal participation is needed. Measures to reduce barriers to mobility in the home and community through targeted assessment for and prescription of assistive technology (e.g., motorized wheelchairs) may be one way to increase the participation of people with SCI in their life situations. Participation may be influenced through efforts to introduce patients with SCI to a variety of exercise and recreational physical activity options. Collaborative partnerships between rehabilitation centers and community-based organizations serving people with physical challenges need to be explored and developed. Pooling human and logistical resources across organizations

to increase the opportunity for exercise and recreational physical activity among people with SCI will reduce cost and is a reasonable measure in a country as small as Singapore and where the economic climate demands increasing accountability. Rehabilitation professionals including physical therapists and occupational therapists can lead in this area. Although only a hypothesis at this stage, greater involvement of full-time, live-in carers through education on the role of carers may assist in community reintegration efforts.

Health promotion needs to begin during inpatient rehabilitation and continued after discharge to assist clients in adopting healthy lifestyle behaviors to prevent secondary and chronic conditions. Programs focused on chronic disease self-management, which increase the self-efficacy of individuals to manage chronic conditions (including physical disability) may be useful adjuncts. In addition to promoting regular physical activity, education about healthy lifestyle behaviors such as not smoking, and optimal nutrition, sleep health and stress management also need to be an integral part of SCI management. Physical therapists and other rehabilitation professionals need to be equipped to counsel on these issues either by initiating interventions, referral to others and supporting their interventions or both.

A system of follow-up care for individuals with SCI after discharge from inpatient care is needed. Guidelines are needed to determine the duration for which an individual should continue to be seen by a rehabilitation physician and/or rehabilitation therapists (e.g., physical therapists or occupational therapists), and when care can be transferred to family physicians, rehabilitation therapists or the family.

The above recommendations are in line with the government's initiative to develop an inclusive society for people with disabilities in Singapore.⁵ Because the government aims to provide an appropriate infrastructure for this initiative, rehabilitation professionals need to partner their efforts by educating clients about how to take advantage of increasing opportunities as well as overcome persistent barriers to inclusion. By promoting health and active participation in life's dimensions, rehabilitation professionals may reduce the burden of care of people with SCI and other disabilities in Singapore.

STUDY LIMITATIONS

This study is representative only of survivors of SCI who participated in the inpatient rehabilitation program at one hospital in Singapore, namely, the TTSH-RC. Based on conservative estimates, TTSH-RC, though no longer the only rehabilitation facility to manage the care of people with SCI, care for about 60% of people with SCI who enter a rehabilitation facility in Singapore. The study also over represents people with tetraplegia. One could infer from this that people with paraplegia may be more active and involved in outdoor activity, hence, more challenging to contact for an interview. A postal survey based on self-complete questionnaires may elicit a greater response from this population.

There is also question about the accuracy of the data extraction process. The potential list of participants extracted from the NHG database was shorter than expected. There were individuals known to the study team whose names and contact details were expected to appear on the list of potential participants extracted from the NHG database but did not. Possible explanations for this include a random or systematic error in coding or

it was incomplete, or that an incorrect list of ICD-9 codes was used in extracting the data. Further investigation is indicated to resolve this apparent disparity.

Participation and health status are known to change over the course of an individual's life after SCI. Being descriptive, this cross-sectional study cannot capture this change. Although the post-hoc comparison of CHART and SWLS data between those who had been injured 5 years or more and those injured less than 5 years ago shed some light on this change, a longitudinal study is needed.

The limitations of the use of the CHART and SWLS may reflect differences in social and cultural norms between North America and Singapore, thus, future studies will help to clarify this observation.

FUTURE RESEARCH

This exploratory study has generated many pivotal questions about the health and lifestyle of people with SCI in Singapore particularly in reference to generating a database and registry of such individuals with an evolving component. Suggestions for future research are detailed throughout the discussion and include studies related to community reintegration, participation and their influencing factors; health promotion and the prevention of disease in SCI; and exploration and potential development of culturally sensitive outcome measures of participation and life satisfaction for people with disabilities in Singapore.

CONCLUSION

This is the first study on disability in Singapore that explores the long term health of people with SCI living in the community rather than a primary focus on immediate post-discharge outcomes. It breaks new ground given its initial investigation into participation and subjective well-being (life satisfaction) in a population with physical disability in Singapore.

The results of our study supports that people with SCI may be less healthy than the general population in Singapore. In addition to their reported low participation and life satisfaction, chronic conditions and their associated risk factors are more prevalent in this population. Rehabilitation professionals need to focus more attention on facilitating community reintegration and promoting healthy lifestyles in people with SCI in Singapore. In addition, more resources need to be allocated to further investigate and address this inequality in health status.

TABLES

Table 1. Demographic Information

	Full-Time Carer			p	Time Since SCI			SCI Level		
	N	Yes	No		≥5 y	<5 y	p	Tetra	Para	p
Gender				0.898			0.898			0.642
Male	50	27	23		26	24		40	10	
Female	5	2	3		3	2		3	2	
Ethnicity				0.858			0.858			0.682
Chinese	46	25	21		25	21		36	10	
Malay	9	4	5		4	5		7	2	
Indian	0	0	0		0	0		0	0	
Age (Mean Years)	48.3	51	45.2	0.202	50.4	45.8	0.32	51.1	38	0.005
Marital Status				0.887			0.887			0.018
Not Married	27	14	13		15	12		17	10	
Currently Married	28	15	13		14	14		26	2	
Highest Level of Education				0.965			0.776			0.648
Tertiary	20	11	9		12	8		15	5	
Secondary	24	13	11		12	12		20	4	
Primary and below	10	5	5		5	5		7	3	

SCI – Spinal Cord Injury; Tetra – Tetraplegia; Para – Paraplegia

HDB – Housing Development Board, the public housing authority of Singapore

Table 1. Demographic Information (Continued)

	N	Full-Time Carer		p	Time Since SCI		P	SCI Level		P
		Yes	No		≥5 y	<5 y		Tetra	Para	
Housing										
1-2rm HDB	2	0	2		1	1		1	1	
3-5rm HDB	41	22	19		19	22		32	9	
Private Apt/Condo	4	4	0		3	1		4	0	
Semi-D/D	2	2	0		2	0		1	1	
Other	6	1	5		4	2		5	1	
Employment Status				0.389			0.877			0.979
Employed	7	2	5		4	3		5	2	
Not Employed	48	27	21		25	23		38	10	

SCI – Spinal Cord Injury; Tetra – Tetraplegia; Para – Paraplegia

HDB – Housing Development Board, the public housing authority of Singapore

Table 2. Comparison of Gender, Mean Age, Type of Injury and Time Since Injury between Study Sample and Group of Individuals who were Not Contactable or Declined Participation

	Gender		Mean Age (y)	Type of Injury		Time Since Injury (mth)
	M	F		Tetra	Para	
Study Sample (n=55)	50	5	48.3	43	12	62.5
Individuals Not Contacted or Declined (n=115)	97	18	54.4	60	54	76.9
p value	0.292		0.026	0.001		0.01

Table 3. Classification of Leisure-Time Physical Activity^a

Classification	Description of Classification
Regular Exercise	Participation in at least moderate-intensity sports or exercise for at least 20 minutes, for 3 or more days a week
Occasional Exercise	Participation in at least moderate-intensity sports or exercise for at least 20 minutes, for less than 3 days a week
No Exercise	No participation in any form of sports or exercise that lasted for at least 20 minutes

^aFrom the National Health Surveillance Survey 2007¹¹

Table 4. Prevalence (%) of Lifestyle Behaviors for the Singapore Population and Sample with Traumatic Spinal Cord Injury

	Singapore Residents ^a	Study Sample with Traumatic SCI	
	18-69 y	21-69 y	21-80 y
Regular Exercise	23.6	26.5	25.5
Regular Alcohol Consumption	1.2	2.0	3.6
Binge Drinking	4.4	6.1	5.5
Daily Cigarette Smoking	13.6	14.3	12.7

^aData from the National Health Surveillance Survey 2007¹¹

Table 5. Classification of the Frequency of Alcohol Consumption^a

Classification	Frequency of Alcohol Consumption
Regular Drinker	> 4 days a week
Frequent Drinker	1-4 days a week
Occasional Drinker	≤ 3 days a month

^aFrom the National Health Surveillance Survey 2007¹¹¹

Table 6. Prevalence (%) of Chronic Conditions in the Singapore Population and the Sample with Traumatic Spinal Cord Injury

Chronic Condition	Singapore Residents ^a	Sample with Traumatic SCI	
	18-69 y	21-69 y	21-80 y
Diabetes Mellitus	4.6	8.2	9.1
Hypertension	12	8.2	10.9
High Cholesterol	12.5	20.4	22
Asthma	6.6	8.2	7.2

^aData from the National Health Surveillance Survey 2007¹¹

Table 7. Participants' Scores for the Six Dimensions of the CHART

CHART Scores	Mean	Standard Deviation
Physical Independence (n=45)	85.7	15.17
Cognitive Independence (n=50)	88.4	19.60
Mobility (n=50)	60.5	27.88
Occupation (n=50)	32.2	32.42
Social Interaction (n=50)	70.2	27.55
Economic Self-Sufficiency (n=23)*	75.0	33.71

*Note: May not be 'valid' due to small n

Table 8. Between Groups Comparisons of Mean CHART and SWLS Scores with Participants Stratified According to Presence of Full-Time Carer, Time Since Injury and Type of Injury

	Total Sample	Full-Time Carer		p	Time Since SCI		P	SCI Level		P
		Yes (n=29)	No (n=26)		≥5 y (n=29)	<5 y (n=26)		Tetra (n=43)	Para (n=12)	
CHART (0-100)										
Physical Independence	85.7	76.5	97.2	<0.0001	87.8	83.6	0.217	82.8	94.8	0.022
Cognitive Independence	88.4	84.0	94.6	0.043	90.8	85.9	0.144	88.1	89.3	0.991
Mobility	60.5	49.3	76.0	0.001	65.8	54.8	0.158	58.5	66.8	0.362
Occupation	32.2	22.5	45.6	0.051	33.3	30.9	0.726	27.5	46.9	0.072
Social Interaction	70.2	67.9	73.4	0.751	65.9	74.9	0.170	70.3	70.1	0.987
Economic Self-Sufficiency	75	72.2	76.8	0.954	80.0	71.02	0.373	72.2	85.0	0.375
Satisfaction with Life Scale (SWLS) (5-35)	13.9	14.9	13.9	0.600	14.7	14.1	0.933	15.7	9.8	0.077

SCI – Spinal Cord Injury; Tetra – Tetraplegia; Para – Paraplegia

CHART – Craig Hospital Assessment and Reporting Technique

Table 9. Between Groups Comparisons of Mean CHART and SWLS Scores with Participants Stratified According to Reported Regular Exercise

	Total Sample	Regular Exercise		p
		Yes (n=14)	No (n=31)	
CHART				
Physical Independence	85.7	83.6	86.7	0.911
Cognitive Independence	88.4	86.2	86.2	1.00
Mobility	60.5	70.9	56.5	0.081
Occupation	32.2	48.5	25.8	0.021
Social Interaction	70.2	87.3	63.6	0.006
Economic Self-Sufficiency	75	87.5	72.2	0.466
Satisfaction with Life Scale (SWLS)	13.9	14.4	13.7	0.831

SCI – Spinal Cord Injury; Tetra – Tetraplegia; Para – Paraplegia

CHART – Craig Hospital Assessment and Reporting Technique

Table 10. Spearman's Rho for Correlation between Six CHART Dimensions and SWLS

CHART Dimensions	Satisfaction with Life	p
Physical Independence	0.288	0.056
Cognitive Independence	0.338	0.017
Mobility	0.186	0.196
Occupation	0.111	0.443
Social Interaction	0.152	0.291
Economic Self-Sufficiency	0.21	0.333

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APPENDICES
APPENDIX A



The University of British Columbia
Office of Research Services
**Behavioural Research Ethics
Board**
Suite 102, 6190 Agronomy Road,
Vancouver, B.C. V6T 1Z3

CERTIFICATE OF APPROVAL - FULL BOARD

PRINCIPAL INVESTIGATOR: Elizabeth Dean	INSTITUTION / DEPARTMENT: UBC/Medicine, Faculty of/Physical Therapy	UBC BREB NUMBER: H09-01020
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:		
<small>Institution</small>	<small>Site</small>	
UBC	Vancouver (excludes UBC Hospital)	
<small>Other locations where the research will be conducted: Research site: Tan Tock Seng Rehabilitation Centre, Singapore Interviews will be conducted over the phone or in-person at a place convenient for the study participant.</small>		
CO-INVESTIGATOR(S): Sook Hui Joy Teo		
SPONSORING AGENCIES: Singapore Physiotherapy Association		
PROJECT TITLE: Health of people with spinal cord injury in Singapore: Implications for rehabilitation planning and implementation		
REB MEETING DATE: June 25, 2009	CERTIFICATE EXPIRY DATE: June 25, 2010	
DOCUMENTS INCLUDED IN THIS APPROVAL:		DATE APPROVED: July 8, 2009
<small>Document Name</small>	<small>Version</small>	<small>Date</small>
<u>Consent Forms:</u>		
Consent Form	June 29 2009	July 7, 2009
<u>Questionnaire, Questionnaire Cover Letter, Tests:</u>		
Telephone Contact Script	N/A	May 20, 2009
Questionnaire	N/A	June 2, 2009
The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.		
Approval is issued on behalf of the Behavioural Research Ethics Board		

and signed electronically by one of the following:

Dr. M. Judith Lynam, Chair
Dr. Ken Craig, Chair
Dr. Jim Rupert, Associate Chair
Dr. Laurie Ford, Associate Chair
Dr. Anita Ho, Associate Chair



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DSRB Ref: D/09/133

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www.nhg.com.sg
RCB No. 200002150H

7 May 2009

Ms Sew Woan Yeen, Sharon
Department of Physiotherapy
Tan Tock Seng Hospital

Dear Ms Sew

NHG DOMAIN-SPECIFIC REVIEW BOARD (DSRB) APPROVAL

Project Title: Health Status of People with Spinal Cord Injury in Singapore: Implications for Long-term Rehabilitation Planning and Implementation

We are pleased to inform you that the NHG Domain Specific Review Board has approved the above research project to be conducted in Tan Tock Seng Hospital.

The documents reviewed are:

- a) IRB & DSRB Application Form: Health Status of People with Spinal Cord Injury in Singapore: Implications for Long-term Rehabilitation Planning and Implementation
- b) Participant Information Sheet and Consent Form: **Version dated 5/05/2009**
- c) Questionnaire
- d) Invitation to Participate in Research Study : Telephone Interview Script

The approval period is from **7 May 2009** to **6 May 2010**. The reference number for this study is **DSRB-D/09/133**. Please use this reference number for all future correspondence.

Continued approval is conditional upon your compliance with the following requirements:

1. Only the approved Participant Information Sheet and Consent Form should be used. It must be signed by each subject prior to initiation of any protocol procedures. In addition, each subject should be given a copy of the signed consent form.
2. No deviation from, or changes of the protocol should be implemented without documented approval from the NHG DSRB, except where necessary to eliminate apparent immediate hazard(s) to the study subjects, or when the change(s) involves only logistical or administrative aspects of the trial (e.g. change of monitor or telephone number).
3. Any deviation from, or a change of, the protocol to eliminate an immediate hazard should be promptly reported to the NHG DSRB within seven calendar days.

1 of 2



DSRB Ref: D/09/133

4. Please submit the following to the NHG DSRB:
 - a. All unanticipated problems involving risk to subjects or others, including serious adverse events (SAE) should be reported. In order to assist the DSRB, all reports should be accompanied by the NHG DSRB Unanticipated Problems Involving Risk to Subjects or Others Reporting Form. Please find all forms and guidelines on reporting on the internet at www.b2bresearch.nhg.com.sg.
 - b. Report(s) on any new information that may adversely affect the safety of the subject or the conduct of the study.
 - c. NHG DSRB Project Status Report Form – this is to be submitted 4 to 6 weeks prior to expiry of the approval period. The study cannot continue beyond **6 May 2010** until approval is renewed by the NHG DSRB.
 - d. Study completion – this is to be submitted using the NHG DSRB Project Status Report Form within 4 weeks of study completion or termination.
5. We are happy to inform you that the NHG Research QA Program has been launched in May 2006. The program aims to promote responsible conduct of research in a research culture with high ethical standards, and to identify potential systemic weaknesses and make recommendations for continual improvement. This research project may be randomly selected for completion of self assessment worksheet or for a study review by the QA team. For more information please visit www.b2bresearch.nhg.com.sg.

Yours sincerely,

A/Prof Low Yin Peng
Chairman
Domain Specific Review Board D
National Healthcare Group

Cc: Director of Research, TTSH (via fax only) c/o TTSH CRU
Head, Department of Physiotherapy, TTSH

OFFICIAL USE ONLY	
Doc Name : Consent Document Template	
Doc Number : 207-001	
Doc Version : 2 (G)	Date : 19 Jan 07

PARTICIPANT INFORMATION SHEET

1. Study Information**Protocol Title:**

Health of People with Spinal Cord Injury in Singapore: Implications for Long-Term Rehabilitation Planning and Implementation

Principal Investigator & Contact Details:

Sharon Sew Woan Yeen.

Tel No.: 6450 6182

Address: Tan Tock Seng Rehabilitation Centre

17 Ang Mo Kio Ave 9, Singapore 569766

2. Purpose of the Research Study

You are invited to participate in a research study. It is important to us that you first take time to read through and understand the information provided in this sheet. To ensure your understanding, a researcher involved in this study will call you within the next 2 weeks to re-explain the study to you and give you a chance to ask questions before inviting you decide on your participation.

You are invited because you have survived a spinal cord injury and have been admitted previously to either Tan Tock Seng Rehabilitation Centre (TTHS-RC) for treatment.

This study is carried out to find out about the health and lifestyle of people with spinal cord injury in Singapore so that improvements can be made to rehabilitation and support services for this population.

Researchers involved in this study will invite participation from an estimated 400 individuals who have previously been admitted to TTHS-RC over a period of 4 months (May to August 2009). An estimated 140 subjects will be involved in this study.

3. Your Involvement in this Study

If you agree to take part in this study, you will be asked to participate in one telephone interview. The interview will take about 30 min to complete. You may request for the interview to be performed 'in-person' if this is more convenient or comfortable for you. Furthermore, if you are unable to communicate fluently in English, a proxy who is able to do so can complete the telephone interview on your behalf.

4. Possible Risks and Side Effects

Participating in this study may increase your awareness and concern for certain aspects of your health and lifestyle. At the end of the interview, you may bring up these concerns with the researcher who may be able to help by directing you to appropriate resources or health professionals.

7. Possible Benefits from Participating in the Study

Your participation in this study will add to the currently lacking knowledge about the health and lifestyle of people with spinal cord injury in Singapore. This information may be used to anticipate the needs of this population in Singapore so that better medical and rehabilitation care, as well as support services can be provided. The results of this study will also be a stepping stone for further studies to benefit people with spinal cord injury and other disabilities in Singapore.

10. Costs & Payments if Participating in the Study

On completing the interview, you will receive a \$10 taxi voucher as a token of appreciation for your time and cooperation.

11. Voluntary Participation

Your participation in this study is voluntary. You may stop participating in this study at any time. Your decision not to take part in this study or to stop your participation will not affect your medical care or any benefits to which you are entitled. If you decide to stop taking part in this study, you should tell the investigator who is conducting the interview with you.

The investigator and/or the sponsor of this study may stop your participation in the study at any time if they decide that it is in your best interests. They may also do this if you do not follow instructions required to complete the study adequately.

13. Confidentiality of Study and Medical Records

Information collected for this study will be kept confidential. Your records, to the extent of the applicable laws and regulations, will not be made publicly available.

However, the Sponsoring company (*Singapore Physiotherapy Association*), Regulatory Agencies and NHG Domain-Specific Review Board and Ministry of Health will be granted direct access to your original medical records to check study procedures and data, without making any of your information public.

Data collected and entered into the Case Report Forms are the property of *TTSH-RC*. In the event of any publication regarding this study, your identity will remain confidential

14. Who To Contact if You Have Questions

Sharon Sew Woan Yeen.

Tel No.: 6450 6182

Address: Tan Tock Seng Rehabilitation Centre

17 Ang Mo Kio Ave 9, Singapore 569766

The study has been reviewed by the NHG Domain Specific Review Board (the central ethics committee) for ethics approval.

If you want an independent opinion of your rights as a research subject you may contact the NHG Domain Specific Review Board Secretariat at 6471-3266.

If you have any complaints about this research study, you may contact the Principal Investigator or the NHG Domain Specific Review Board Secretariat.

APPENDIX C

CONSENT FORM

Protocol Title:

A Description of the Health of People with Spinal Cord Injury in Singapore

Principal Investigator & Contact Details:

Sharon Sew Woan Yeen.

Tel No.: 6450 6182

Address: Tan Tock Seng Rehabilitation Centre

17 Ang Mo Kio Ave 9, Singapore 569766

Investigator Statement

I, the undersigned, certify that I explained the study to the participant and to the best of my knowledge the participant clearly understands the nature, risks and benefits of her participation in the study. The participant, _____ provided verbal consent to participate in this study.

Name of Investigator

Signature

Date

CONSENT FORM

Protocol Title:

Health of People with Spinal Cord Injury in Singapore: Implications for Long-Term Rehabilitation Planning and Implementation

Principal Investigator & Contact Details:

Sharon Sew Woan Yeen.

Tel No.: 6450 6182

Address: Tan Tock Seng Rehabilitation Centre

17 Ang Mo Kio Ave 9, Singapore 569766

I voluntarily consent to take part in this research study. I have fully discussed and understood the purpose and procedures of this study. This study has been explained to me in a language that I understand. I have been given enough time to ask any questions that I have about the study, and all my questions have been answered to my satisfaction.

Name of Investigator

Signature

Date

Investigator Statement

I, the undersigned, certify that I explained the study to the participant and to the best of my knowledge the participant signing this informed consent form clearly understands the nature, risks and benefits of her participation in the study.

Name of Investigator

Signature

Date

Invitation to Participate in Research Study

Telephone Interview Script

“Good morning / afternoon / evening, my name is (investigator’s name) I am calling from Tan Tock Seng Rehabilitation Centre. May I please speak with (name of potential participant) .” How may I address you?

“A letter was recently sent to you offering a \$10 taxi voucher for taking part in a research project on the health of people with spinal cord injury. Have you received it? Do you have any questions about the research project? I would like to give you more information on this project and invite you to take part. Are you comfortable with me continuing in English? “

(If participant not comfortable to communicate in English, ask if there is proxy available to answer phone on his / her behalf. Reintroduce yourself and repeat above info if necessary)

(If participant agrees to continue with conversation...)

“Before I continue, I need to ask you a few questions to make sure that you meet the criteria to take part in this study. Is that okay?

1. Have you had a spinal cord injury? Yes / No

2. How did you sustain your injury? 1. RTA 2. Injury at work 3.

Others: _____

3. Is your injury work related? (Do not ask if already determined in above qn) Yes / No

4. When you were injured, were you admitted to Tan Tock Seng Rehab Centre for treatment?

Yes / No

5. When were you admitted (month / year)? _____

6. When were you discharged (from TTSH incl. rehab stay) (month / year)?

7. How long were you in hospital for? _____

8. How old are you? _____

9. What is your date of birth (day / month / year)? _____

10. Have you ever been told that you had a brain injury? Yes / No

11. Do you have any cognitive problems that affects your day to day functioning (e.g. memory, word finding)? Yes / No

12. Are you Singaporean? Yes / No

(Check date of admission, discharge, length of stay, age and date of birth against available demographic data to ensure accuracy and as a screen of cognitive status. If participant able to provide generally accurate information, continue as follows. *If not, use discretion to determine if client is cognitively competent. If necessary, inform the individual that he or she does not meet the criteria necessary to participate in the study. Thank the individual for his/her time before ending the conversation.*)

“You meet the criteria for the study. May I briefly run through the purpose and procedure of the study?”

We realise that living with SCI is often very challenging but we don’t have much information about what it’s like to live with a SCI in Singapore and the difficulties that people like yourself may face every day. So the purpose of this study is to find out about the health and lifestyle of people with SCI so that better services can be provided in the future for people like yourself.

If you agree to take part, I will ask you some questions about your health (for example, if you have certain medical conditions), how often you see the doctor as well as your daily activities. It will take about 30 minutes. You can answer these questions on the phone or I can meet with you to conduct the interview somewhere convenient for you. Do you have any questions?”

(Answer participant’s questions)

“After you complete the interview, we will send you a \$10 taxi voucher. Taking part in this study is entirely voluntary. The information you provide me will not be linked to your name or IC number. Your name will not be revealed in study reports. You are free to stop the interview at any time. Your decision to take part or not will not affect your medical care or any benefits to which you are entitled. ”

“Would you be willing to take part in this study?”

(IF YES – document consent on “CONSENT FORM”)

“Would you like to perform the interview on the phone or in person?”

(If ‘in-person’, make arrangements to meet the participant at a time and place convenient for him or her. Repeat details of appointment and thank the participant before ending the conversation.)

(If participant would like to perform interview on the phone but is not available now, arrange a time to call again for the

(If participant would like to perform interview on the phone and is available now, continue as follows...)

“Thank you for your willingness to participate. The questions in the interview may raise concerns for you about your health and lifestyle. At the end of the interview, I will give you an opportunity to ask questions about these concerns.

I shall begin by asking you a few background questions before asking you questions on your health. Would you like to get your copy of the questionnaire to follow along?”

(Proceed to perform interview.)

(IF NO)

“Would you be willing to take part in this study at another time or place?”

(If so, make arrangements to perform interview at another time or place.)

“Do you have any other concerns preventing you from taking part in this study?”

(Address these concerns if present. If not, thank the participant for their time before concluding the conversation.)

APPENDIX E

DEMOGRAPHICS

<READ OUT ALL OPTIONS UNLESS INDICATED OTHERWISE>

1001. <DO NOT ASK> Record sex as observed

Male	1
Female	2

1002. What is your / (participant's name) racial group?

Chinese	1
Malay	2
Indian	3
Others (specify): _____	4

1003. What is your / (participant's name) date of birth?

1004. What is your / (participant's name) current marital status?

Never married	1
Currently married	2
Separated	3
Divorced	4
Widowed	5
Not answered	999

1005. What is the highest level of education* that (participant's name) / you has / have attained?

No formal / qualifications / primary	1
PSLE	2
Secondary	3
'O' / 'N' level	4
'A' level	5
Polytechnic diploma	6
Other diploma & professional qualification	7
University	8
Don't know	000
Not answered	999

*Refers to the highest level or standard which a person had passed or attained and awarded a certificate, either through attendance at an institution of learning or through correspondence or self-study.

1006. What is your / (participant's name) main work status over the last 12 months?

Working (record occupation below)	1	Working means employed at least 6 months out of 12.
Student (full-time)	2	
National Service	3	
Homemaker / Housewife	4	
Retired (record previous occupation below)	5	
Unemployed (able to work) (record previous occupation below)	6	To distinguish between 6 or 7 ask: "Why are you unemployed?"
Unemployed (unable to work)* * due to disability or other medical conditions	7	
Not answered	999	

Occupation: _____

1007. What type of housing do you / (participant's name) live in now?

1 or 2-room flat (HDB)	1
3, 4 or 5-room flat (HDB)	2
Apartment / condominium (not HDB)	3
Detached / semi-detached house	4
Other _____	5
Not answered	999

IF PROXY:

1008. How are you related to (participant's name)?

- | | |
|------------------------|---|
| Parent | 1 |
| Child | 2 |
| Relative | 3 |
| Friend | 4 |
| Paid Carer (e.g. maid) | 5 |
| Other (specify): _____ | 6 |
| _____ | |

1009. Do you live with (participant's name)?

- | | |
|-----|---|
| Yes | 1 |
| No | 2 |

INJURY INFORMATION

<READ OUT ALL OPTIONS UNLESS INDICATED OTHERWISE>

2001. How did you / (participant's name) get injured?

Road traffic accident	1
Injury at work	2
Other (specify)_____	3
Don't know	000
Not answered	999

2002. How long have you / (participant's name) been injured?

____ years ____ months

Don't know	000
Not answered	999

2003. At what level of the spinal cord is your / (participant's name) injury?

Don't know	000
Not answered	999

2004. Can you / (participant's name) feel anything below the level of your /his/her spinal cord injury?

Yes	1
No	2

2005. Can you / (participant's name) move any muscles below the level of your/his/her spinal cord injury?

Yes 1

No 2

2006. Are/Is you / (participant's name) able to eat independently?

Yes 1

No 2

2007. Are/Is you / (participant's name) able to walk?

Yes 1

Yes, with assistive devices 2

No 3

2008. What is your / (participant's name) main mode of mobility?

Wheelchair (manual) 1

Wheelchair (power) 2

Walk 3

Walk with assistive devices 4

PHYSICAL ACTIVITY

<READ OUT>: Please think about the time you spend doing work since your injury. Think of work as the things that you **have to do** such as paid or unpaid work, and household chores or looking for a job (exclude personal care activities.)

<READ OUT ALL OPTIONS UNLESS INDICATED OTHERWISE>

3001. Does your work involve vigorous activity, like (heavy lifting, digging or construction work) for at least 10 minutes at a time?

Yes	1
No	2 (Go to Q. 3003)

3002. In a typical week, on how many days do you do vigorous activities as part of your work?

____ Days a week	
Don't know	000
Not answered	999

3002a. On a typical day in which you do vigorous activity, how much time (in total) do you spend doing such activity?

____ hrs ____ mins	
Don't know	000
Not answered	999

3003. Does your work involve moderate-intensity activity, like (mopping the floor or carrying light loads)

Yes	1
No	2 (Go to Q. 3005)

3004. In a typical week, on how many days do you do moderate-intensity activities as part of your work?

____ Days a week

Don't know 000

Not answered 999

3004a. On a typical day in which you do moderate-intensity activity, how much time (in total) do you spend doing such activity?

____ hrs ____ mins

Don't know 000

Not answered 999

3005. How long is your typical work day? (including time spent on household chores)

____ hours

Don't know 000

Not answered 999

<READ> I would like to ask you about the way you travel to and from places. For example, to work, for shopping, to market, or to (church, temple or mosque) or going out for lunch.

3006. Do you *propel your wheelchair or walk for at least 10 minutes continuously to travel from one place to another?

Yes 1

No 2 (Go to Q. 3009)

3007. In a usual week, on how many days do you *propel your wheelchair or walk for at least 10 minutes at a time from one place to another?

____ Days a week

Don't know 000

Not answered 999

3007a. On a typical day when you *propel your wheelchair or walk for at least 10 minutes at a time, how much time in total do you spend walking or pushing your wheelchair?

____ hrs ____ mins

Don't know 000

Not answered 999

<READ> Next, I would like to ask you about activities you do in your leisure time. Think about activities you do for recreation, fitness or sports. Do not include physical activities you do at work or for travel.

3008. In the past 3 months, did you participate in any sports, exercise, walking or propelling your wheelchair during your leisure time?

Yes 1 (Go to 3008b)

No 2 (Go to 3008a)

If NO:

3008a. What is your main reason for not doing any leisure physical activity?

<DO NOT READ OUT OPTIONS>

No time due to work / family commitment	1
No companion to exercise with	2
Too lazy	3
Too tired because of work commitment etc	4
Too old	5
Poor health	6
Doctor advise not to exercise	7
Have enough exercise at work	8
Lack of facilities	9
Weather is too hot / humid	10
Others (specify): _____	11

Don't know	000
Not answered	999

If YES:

3008b. In the past 3 months, what were the sports or exercise you participated in?

<DO NOT READ OUT OPTIONS>

Don't know	000
Not answered	999

No.	Activities	Frequency (no. of sessions/wk)	Duration per session (mins)	Intensity* 1 light 2 moderate 3 vigorous
1	Running or jogging			
2	Swimming			
3	Walking (for leisure)			
4	Soccer			
5	Badminton			
6	Cycling			
7	Gym-workout (weights)			
8	Gym-workout (treadmill, power rider, stationary bike)			
9	Basketball			
10	Golf			
11	Tennis			
12	Aerobic exercise			
13	Billiards / Snooker / Pool			
14	Bowling			
15	Body building / weight lifting			
16	Canoeing or rowing			
17	Dancing (all forms)			
18	Hiking / Mountain climbing			
19	Martial Arts / Taekwando / Karate / Judo / Silat / Lion Dance			

20	Netball			
21	Roller skate / In-line skating / Ice skating / Roller blading / Skate boarding			
22	Rock climbing			
23	Rugby			
24	Sailing (including yachting)			
25	Sepat takraw			
26	Softball			
27	Squash			
28	Stretching and muscle toning exercise (sit up, push up, knee bending, leg stretching)			
29	Taichi / Qigong			
30	Table tennis			
31	Yoga			
32	Handcycling			
	Other Sports			
32	Others (specify):			
33	Others (specify):			
34	Others (specify):			
35	Others (specify):;			

* **Vigorous** physical activities – make you breathe **much harder** than normal..... 1
Moderate physical activities – make you breathe **somewhat harder** than normal..... 2
Light physical activities – **no change** in breathing pattern 3

CIGARETTE SMOKING

<READ OUT ALL OPTIONS UNLESS INDICATED OTHERWISE>

4001. Have you ever smoked cigarettes?

Yes	1
No	2 (Go to Q. 5001)

4002. Do you smoke now?

Daily*	1 (Go to Q. 4003)
Occasionally	2 (Go to Q. 5001)
Have stopped smoking completely	3 (Go to Q. 5001)
Not answered	999

* includes respondents who have to stop smoking daily temporarily because of religious fasting or medical reasons

Daily Smoker Only

4003. On average, how many cigarettes do you smoke per day?

____ cigarettes	
Don't know	000
Not answered	999

4004. What is your main reason for smoking now?

<DO NOT READ OUT OPTIONS>

To feel relaxed / to relieve stress / to help me cope with problems	1
To help me concentrate	2
Would feel unbearable if I do not smoke	3
Smoking is enjoyable	4
Boredom	5
To feel confident / grown up / important	6
To be liked by family members / relatives	7
To model film / TV stars	8
To be liked / impress my boyfriend / girlfriend / friends / colleagues	9
To entertain clients / friends	10
Others (specify) : _____	11

Don't know	000
Not answered	999

ALCOHOL CONSUMPTION

<READ OUT ALL OPTIONS UNLESS INDICATED OTHERWISE>

5001. Have you ever consumed alcohol?

- | | |
|-----|-------------------|
| Yes | 1 |
| No | 2 (Go to Q. 6001) |

5002. Have you consumed alcohol in the past 12 months?

- | | |
|-----|-------------------|
| Yes | 1 |
| No | 2 (Go to Q. 6001) |

5003. In the past 12 months, how frequently have you had at least one drink?

- | | |
|------------------------|-----|
| 5 or more days a week | 1 |
| 1-4 days per week | 2 |
| 1-3 days a month | 3 |
| Less than once a month | 4 |
| Don't know | 000 |
| Not answered | 999 |

5004. When you drink alcohol, on average, how many glasses have you had during one day?

____ drinks

Don't know 000

Not answered 999

5005. During the past month, have you ever had 5 drinks or more in any one drinking session?

Yes 1

No 2 (Go to Q. 6001)

If YES:

5006. How many times?

____ times

Don't know 000

Not answered 999

SLEEP AND STRESS

<READ OUT ALL OPTIONS UNLESS INDICATED OTHERWISE>

6001. On average, how many hours do you sleep a night?

_____ hours	
Don't know	000
Not answered	999

6002. Do you sleep soundly?

Yes	1
No	2
Sometimes	3

6003. How would you describe the stress level in your life?

High	1
Moderate	2
Low	3 (Go to Q. 7001)
Don't know	000
Not answered	999

6004. What do you think needs to change to reduce your life stress?

<DO NOT READ OUT OPTIONS>

<ALLOW MORE THAN ONE ANSWER>

Social network	1
Income	2
Living conditions	3
Community accessibility	4
Employment	5
Physical health status	6
Medical / rehabilitation / hospital services / facilities	7
Other (specify): _____	8
<hr/>	
Don't know	000
Not answered	999

DIABETES

<READ OUT ALL OPTIONS UNLESS INDICATED OTHERWISE>

7001. Have you ever been told by a doctor that you have diabetes?

Yes	1
No	2 (Go to Q. 8001)
Don't know	000 (Go to Q. 8001)
Not answered	999 (Go to Q. 8001)

7001a. What type of medication are you on?

None	1
Insulin injections	2
Oral hypoglycemic agents	3
Both insulin injections & oral hypoglycemic agents	4
Others (specify): _____ _____	5
Don't know	000
Not answered	999

7001b. How many years have you had diabetes?

____ years	
Don't know	000
Not answered	999

7001c. What do you do to control your diabetes?

<ALLOW MORE THAN ONE ANSWER>

Lose weight	1
Reduce salt intake	2
Reduce fat intake	3
Exercise	4
Cutting down / stop smoking	5
Reduce / cope with stress	6
Other (specify): _____	7

None	8
Don't know	000
Not answered	999

7002. About how many times in the last 12 months have you seen a doctor for your diabetes?

_____ times	
Don't know	000
Not answered	999

7003. Where do you seek treatment for your diabetes most of the time?

Private GP	1
Government polyclinic	2
Specialist outpatient clinic (restructured hospital)	3
Specialist outpatient clinic (private hospital)	4
Others (specify):_____	5

None	6
Don't know	000
Not answered	999

HYPERTENSION

8001. Have you ever been told by a doctor that you have high blood pressure?

Yes	1
No	2 (Go to Q. 9001)
Don't know	000 (Go to Q. 9001)
Not answered	999 (Go to Q. 9001)

8001a. How many years have you had high blood pressure?

____ years

Don't know	000
Not answered	999

8001b. Does your doctor currently prescribe tablets for your high blood pressure?

Yes	1
No	2

8001c. What do you do to control your blood pressure?

<ALLOW MORE THAN ONE ANSWER>

Lose weight	1
Reduce salt intake	2
Reduce fat intake	3
Exercise	4
Cutting down / stop smoking	5
Reduce / cope with stress	6

Other (specify): _____	7
<hr/>	
None	8
Don't know	000
Not answered	999

8001d. How long ago was your most recent blood pressure check done?

Less than one month	1
1 to 3 months	2
4 to 6 months	3
More than 6 months	4
Don't know	000
Not answered	999

8002. About how many times in the last 12 months have you seen a doctor for your high blood pressure?

____ times	
Don't know	000
Not answered	999

8003. Where do you seek treatment for your high blood pressure most of the time?

Private GP	1
Government polyclinic	2
Specialist outpatient clinic (restructured hospital)	3
Specialist outpatient clinic (private hospital)	4
Others (specify):_____	5

None	6
Don't know	000
Not answered	999

HEALTH CONDITIONS

9001. Have you ever been told by a doctor that you have chest pain due to heart problems?

Yes	1
No	2
Don't know	000
Not answered	999

9002. Have you ever been told by a doctor that you had a heart attack?

Yes	1
No	2
Don't know	000
Not answered	999

9003. Have you ever been told by a doctor that you had a stroke?

Yes	1
No	2
Don't know	000
Not answered	999

9004. Have you ever been told by a doctor that you have arthritis?

Yes	1
No	2
Don't know	000
Not answered	999

9005. Have you ever been told by a doctor that you have asthma?

Yes	1
No	2
Don't know	000
Not answered	999

9006. Have you ever been told by a doctor that you have high blood cholesterol or lipids?

Yes	1
No	2
Don't know	000
Not answered	999

9007. Have you ever been told by a doctor that you are overweight or you need to lose weight?

Yes	1
No	2
Don't know	000
Not answered	999

9008. Have you ever been told by a doctor that you have cancer?

Yes	1
No	2
Don't know	000
Not answered	999

9009. Have you ever been told by a doctor that you have a smoking-related condition like emphysema or chronic bronchitis?

Yes	1
No	2
Don't know	000
Not answered	999

Emphysema / Chronic bronchitis = Smoking related lung problems

HEALTH SERVICES UTILISATION PRACTICES

10001. During the past 3 months, have you visited a private general practitioner (GP) or the government polyclinic for a medical condition?

(visits for screening or immunization are excluded)

Yes	1
No	2 (Go to Q. 10003)
Don't know	000 (Go to Q. 10003)
Not answered	999 (Go to Q. 10003)

10002. What was the main medical condition for which you sought treatment from your GP / polyclinic doctors?

Don't know	000
Not answered	999

Specialist Outpatient Clinic

10003. During the past 3 months, have you visited a specialist for a medical condition?

- | | |
|--------------|----------------------|
| Yes | 1 |
| No | 2 (Go to Q. 10004) |
| Don't know | 000 (Go to Q. 10004) |
| Not answered | 999 (Go to Q. 10004) |

10003a. Which speciality?

<READ OUT EACH OPTION AND CIRCLE IF ANSWER IS 'YES'>

- | | |
|-------------------------|-----|
| General surgery | 1 |
| Orthopaedics surgery | 2 |
| Eye | 3 |
| ENT | 4 |
| Gynaecology | 5 |
| Urology | 6 |
| General medicine | 7 |
| Rehabilitation Medicine | 8 |
| Cardiology | 9 |
| Psychiatry | 10 |
| Others (specify)_____ | 11 |
| <hr/> | |
| Don't know | 000 |
| Not answered | 999 |

Hospitalisation

10004. In the past 12 months, how many times have you been hospitalized?

_____ times (If zero times, go to Q. 11001)

10004a. Why were you hospitalized?

<READ OUT EACH OPTION AND CIRCLE IF ANSWER IS 'YES'>

Pressure sores	1
Urinary tract infections	2
Kidney or bladder stones	3
Pneumonia	4
Bowel obstructions	5
Loss of function	6
Surgical removal of spinal instrumentation	7
Respite	8
Others (specify) _____	9
Don't know	000
Not answered	999

10004b. How long were you in hospital for?

_____ days

Don't know	000
Not answered	999

SCI RELATED SECONDARY IMPAIRMENTS

11001. In the past 12 months, which of the following problems have you experienced?

<READ OUT EACH OPTION AND CIRCLE IF ANSWER IS "YES">

Bladder problems	1
Bowel problems	2
Spasms	3
Pain	4
Swelling (Oedema)	5
Pressure sores	6
Increasing weight	7
Excessive sweating	8
Contractures	9
Breathing / respiratory tract problems	10
Bone formation in muscle (Neurogenic heterotropic ossification)	11
Low blood pressure	12
Blood clots (Thrombosis)	13
Other _____	14
None	15
Not answered	999

CRAIG HOSPITAL ASSESSMENT AND REPORTING TECHNIQUE

<READ> People with disabilities often need assistance. I would like to differentiate between personal care for physical disabilities and supervision for cognitive problems. First, I would like you to focus on physical “hands on” assistance: This includes help with eating, grooming, bathing, dressing, management of a ventilator or other equipment, transfers etc. Keeping in mind these daily activities...

<READ OUT ALL OPTIONS UNLESS INDICATED OTHERWISE>

1. How many hours in a typical 24-hour day do you have someone with you to provide physical assistance for personal care activities such as eating, bathing, dressing, toileting and mobility? How many hours is paid assistance? How many hours is unpaid i.e. help from family or others?

____ hours paid assistance

____ hours unpaid

Don't know 000

Not answered 999

2. Not including any regular care as reported above, how many hours in a typical month do you occasionally have assistance with things such as grocery shopping, laundry, housekeeping, or infrequent medical needs because of the disability?

____ hours per month

Don't know 000

Not answered 999

3. Who takes responsibility for instructing and directing your attendants and/or caregivers?

____ Yourself

____ Someone else

____ You do not use attendant care

<READ> Now please focus on supervision for cognitive problems instead of physical assistance. This includes remembering, decision making, judgement, etc...

4. How much time is someone with you in your home to assist you with activities that require remembering, decision making or judgment? Choose one of the following options:

____ (1) Someone else is always with you to observe or supervise.

____ (2) Someone else is always around, but they only check on you now and then.

____ (3) Sometimes you are left alone for an hour or two.

____ (4) Sometimes you are left alone for most of the day

____ (5) You have been left alone all day and all night, but someone checks in on you.

____ (6) You are left alone without anyone checking on you.

Don't know 000

Not answered 999

5. How much of the time is someone with you to help you with remembering, decision making, or judgment when you go away from your home? Choose one of the following options:

____ (1) You are restricted from leaving, even with someone else.

____ (2) Someone is always with you to help with remembering, decision making or judgment when you go anywhere.

____ (3) You go to places on your own as long as they are familiar.

____ (4) You do not need help going anywhere.

Don't know 000

Not answered 999

6. How often do you have difficulty communicating with other people?

___ You almost always have difficulty.

___ You sometimes have difficulty.

___ You almost never have difficult.

Don't know 000

Not answered 999

7. How often do you have difficulty remembering important things that you must do?

___ You almost always have difficulty.

___ You sometimes have difficulty.

___ You almost never have difficulty.

Don't know 000

Not answered 999

8. How much of your money do you control? Choose one of the following options:

___ (1) None, someone makes all money decisions for you.

___ (2) A small amount of spending money is given to you periodically.

___ (3) Most of your money, but someone helps you make major decisions.

___ (4) You make all your money decisions (or if married, in joint participation with your partner).

Don't know 000

Not answered 999

<READ> Now I have a series of questions about your typical activities.

9. On a typical day, how many hours are you out of bed?

___ hours

Don't know 000

Not answered 999

10. In a typical week, how many days do you get out of your house and go somewhere?

___ days

Don't know 000

Not answered 999

11. In the last year, how many nights have you spent away from your home (excluding hospitalizations?)

___ none ___ 1-2 nights ___ 3-4 nights ___ 5 or more nights

Don't know 000

Not answered 999

12. Can you enter and exit your home without any assistance from someone?

___ Yes ___ No

13. In your home, do you have independent access to your sleeping area, kitchen, bathroom, telephone, and TV (or radio)?

___ Yes ___ No

14. Can you use your transportation independently? (Clarification: Can you organize the transportation yourself, without help?)

___ Yes ___ No

15. Does your transportation allow you to get to all the places you would like to go?

___ Yes ___ No

16. Does your transportation let you get out whenever you want?

___ Yes ___ No

17. Can you use your transportation with little or no advance notice? (Clarification: Don't have to plan far in advance)

___ Yes ___ No

18. How many hours per week do you spend working in a job for which you get paid?

<DO NOT ASK IF PARTICIPANT IS UNEMPLOYED>

___ hours (occupation: _____)

Don't know 000

Not answered 999

19. How many hours per week do you spend in school working toward a degree or in an accredited technical training program (including hours in class and studying)?

___ hours

Don't know 000

Not answered 999

20. How many hours per week do you spend in active homemaking including parenting, housekeeping, and food preparation?

____ hours

Don't know 000

Not answered 999

21. How many hours per week do you spend in home maintenance activities such as gardening, house repairs or home improvement? <RECORD "0" IF PARTICPANT DOES NOT PERFORM THESE ACTIVITIES EVERY WEEK>

____ hours

Don't know 000

Not answered 999

22. How many hours per week do you spend in ongoing volunteer work for an organization?

____ hours

Don't know 000

Not answered 999

23. How many hours per week do you spend in recreational activities such as sports, exercise, playing cards, or going to the movies? Please do not include time spent watching TV or listening to the radio.

____ hours

Don't know 000

Not answered 999

24. How many hours per week do you spend in other self-improvement activities such as hobbies or leisure reading? Please do not include time spent watching TV or listening to the radio.

_____ hours

Don't know 000

Not answered 999

25. Do you live alone? _____ Yes _____ No (If yes, skip to question 26)

25a. Do you live with a spouse or significant other?

_____ Yes _____ No

25b. How many children do you live with? _____

25c. How many other relatives do you live with? _____

25d. How many roommates do you live with? _____

25e. How many attendants do you live with? _____

26. Are you involved in a romantic relationship?

_____ Yes _____ No _____ N/A (Subject lives with spouse or sig. other)

27. How many relatives (not in your household) do you visit, phone, or write to at least once a month?

_____ relatives

Don't know 000

Not answered 999

28. How many business or organizational associates do you visit, phone, or write to at least once a month?

____ associates

Don't know 000

Not answered 999

29. How many friends (non-relatives contacted outside business or organization settings) do you visit, phone, or write to at least once a month?

____ friends

Don't know 000

Not answered 999

30. With how many strangers have you initiated a conversation in the last month (for example, to ask information or place an order)?

____ None ____ 1-2 ____ 3-5 ____ 6 or more

Don't know 000

Not answered 999

31. Approximately what was the combined annual income, in the last year, of all family members in your household? (Consider all sources including wages and earnings, disability benefits, pensions and retirement income, income from court settlements, investments and trust funds, child support and alimony, contributions from relative and any other source.)

\$ _____

Don't know 000

Not answered 999

32. Approximately how much did you pay last year for medical care expenses?
(Consider any amounts paid by yourself or the family members in your household and not reimbursed by insurance or benefits.) <ONLY INCLUDE "MEDISAVE" AND "CO-SHARE" PORTION OF INSURANCE E.G. MEDISHIELD>

\$ _____

Don't know 000

Not answered 999

SATISFACTION WITH LIFE SCALE (SWLS)

<READ> I am going to read five statements with which you may agree or disagree. Please be open and honest in your responding.

1. Do you agree, disagree or neither agree or disagree with this statement?

In most ways my life is close to ideal.

a. (If agree) How much do you agree?

Strongly agree 7

Agree 6

Slightly agree 5

b. (If in the middle) If you had to choose, would you agree or disagree with the statement or are you right in the middle?

Slightly agree 5

Neither agree or disagree 4

Slightly disagree 3

c. (If disagree) How much do you disagree?

Slightly disagree 3

Disagree 2

Strongly disagree 1

2. Do you agree, disagree or neither agree or disagree with this statement?

The conditions of my life are excellent.

a. (If agree) How much do you agree?

Strongly agree 7

Agree 6

Slightly agree 5

b. (If in the middle) If you had to choose, would you agree or disagree with the statement or are you right in the middle?

Slightly agree 5

Neither agree or disagree 4

Slightly disagree 3

c. (If disagree) How much do you disagree?

Slightly disagree 3

Disagree 2

Strongly disagree 1

3. Do you agree, disagree or neither agree or disagree with this statement?

I am satisfied with my life.

a. (If agree) How much do you agree?

Strongly agree 7

Agree 6

Slightly agree 5

b. (If in the middle) If you had to choose, would you agree or disagree with the statement or are you right in the middle?

Slightly agree 5

Neither agree or disagree 4

Slightly disagree 3

c. (If disagree) How much do you disagree?

Slightly disagree 3

Disagree 2

Strongly disagree 1

4. Do you agree, disagree or neither agree or disagree with this statement?

So far I have gotten the important things I want in life.

a. (If agree) How much do you agree?

Strongly agree 7

Agree 6

Slightly agree 5

b. (If in the middle) If you had to choose, would you agree or disagree with the statement or are you right in the middle?

Slightly agree 5

Neither agree or disagree 4

Slightly disagree 3

c. (If disagree) How much do you disagree?

Slightly disagree 3

Disagree 2

Strongly disagree 1

5. Do you agree, disagree or neither agree or disagree with this statement?

If I could live my life over, I would change almost nothing.

a. (If agree) How much do you agree?

Strongly agree 7

Agree 6

Slightly agree 5

b. (If in the middle) If you had to choose, would you agree or disagree with the statement or are you right in the middle?

Slightly agree 5

Neither agree or disagree 4

Slightly disagree 3

c. (If disagree) How much do you disagree?

Slightly disagree 3

Disagree 2

Strongly disagree 1

We have come to the end of the interview. Thank you for taking time to participate. Do you have any questions or concerns?

We will be sending you the taxi voucher. May I confirm your address?

Would you like a copy of the summary of the results when the study is complete?

Yes / No

Thank you again for your time.