

Spinal Cord Injury and Quality of Life:

What Determines Quality of Life and What is the Relationship Between Physical Activity, Fitness and Quality of Life

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ABSTRACT

This thesis is comprised of two investigations. The first investigation, using naturalistic inquiry, determined the domains that represented quality of life for persons with a spinal cord injury. Seven persons with complete quadriplegic injuries (one female, six males) and eight persons with complete paraplegic injuries (five females, three males) participated in this study. Results showed that quality of life for this population, regardless of severity of impairments, was represented by nine domains: 1) physical function and independence; 2) accessibility; 3) emotional well being; 4) stigma; 5) spontaneity; 6) relationships and social function; 7) occupation; 8) finances; and 9) physical well being. The domains of life quality were similar for quadriplegic and paraplegic individuals; however, physical function and independence and physical well being affected the quality of life of persons with a quadriplegic injury to a greater extent. These findings may provide health professionals with information necessary to assist in the development of programs to enhance quality of life.

The objective of the second investigation in this thesis was to explore the relationships amongst four variables of interest; subjective and objective quality of life scores, and fitness and physical activity in individuals with a spinal cord injury. Both qualitative and quantitative methodologies were utilized in this second study and qualitative data collection was done in conjunction with Study One. The same 15 persons described in Study One, in addition to discussing quality of life, also provided information about physical activity and fitness and the role it played in their quality of life. Quantitative data collection with 40 individuals with spinal cord injury included measurements of: fitness, physical activity, subjective quality of life and objective quality of life. Results were reported for each of three level of injury groupings (high quadriplegia, low quadriplegia and paraplegia). Results showed that physical activity was significantly correlated with the total score for objective quality of life in the groups of persons with high quadriplegia and paraplegia. Qualitative results supported these findings especially in relation to the importance of fitness and physical activity to the objective domain of functional ability. There were no significant correlations between subjective quality of life and the other three primary variables; objective quality of life, fitness and physical activity, for any of the level of injury groupings. However,

qualitative results suggested that activity may play an important role in an individual's perception of quality of life. Thus, although the results from this investigation suggest a relationship between fitness, physical activity and objective quality of life, the relationship with subjective quality of life requires further exploration.

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DEDICATION

This thesis is dedicated to all the persons with spinal cord injury in Saskatchewan who over the past seven years have taught me about real courage and the importance of attitude in all of our lives.

*“The Spring never makes the song, I guess
As much as the song the Spring”.*

Douglas Malloch

TABLE OF CONTENTS

PERMISSION TO USE	i
ABSTRACT	ii
ACKNOWLEDGEMENTS	iv
DEDICATION	v
TABLE OF CONTENTS	vi
LIST OF TABLES	viii
LIST OF FIGURES	viii
CHAPTER 1	
1.1. Introduction	1
1.1.1 Operational Definitions	3
1.2. Review of the Literature	4
1.2.1 Spinal Cord Injury – Incidence, Prevalence and Causes	4
1.2.2 Anatomy of the Spine and the Spinal Cord	5
1.2.3 Classification of Spinal Cord Injury	5
1.2.4 Functional Ability in Relation to Neurological Level of Injury	7
1.2.5 Exercise Capabilities of Persons with Spinal Cord Injury	9
1.2.6 Quality of Life and Its Measurement in Spinal Cord Injury	11
1.2.7 The Relationship between Fitness, Physical Activity and Quality of Life	16
1.3 Statement of the Problem	
1.3.1 Determining the Components of Quality of Life for Persons with Spinal Cord Injury	21
1.3.2 Determining the Relationship between Quality of Life and Fitness and Physical Activity for Persons with Spinal Cord Injury	22
CHAPTER 2	
2.1 Study One - Determining the Components of Quality of Life for Persons with Spinal Cord Injury	23
2.1.1 Introduction	23
2.1.2 Methods	24
2.1.3 Results	27
2.1.4 Discussion	39
2.2 Study Two - Determining the Relationship between Quality of Life and Fitness and Physical Activity for Persons with Spinal Cord Injury	44
2.2.1 Introduction	44
2.2.2 Methods	45
2.2.3 Results	
2.2.3.1 Quantitative Results	57
2.2.3.2 Qualitative Results	69
2.2.4 Discussion	72

CHAPTER 3	
General Discussion	81
3.1 Implications for Health Professionals	83
CHAPTER 4	
Conclusions and Future Research	85
REFERENCES	87
APPENDIX 1 Consent Form Study 1	95
APPENDIX 2 Semi Structured Interview Guide Study	97
APPENDIX 3 Consent Form Study 2	98
APPENDIX 4 Background Information Questionnaire	100
APPENDIX 5 Quality of Life Profile: Physical and Sensory Disabilities Version	102
APPENDIX 6 Craig Handicap Assessment Reporting Technique (CHART)	126
APPENDIX 7 Physical Activity Questionnaire	128

List of Tables

Chapter 2.2 Determining the Relationship between Quality of Life and Fitness and Physical Activity for Persons with Spinal Cord Injury

2.2.1 Age, Duration of Injury, Physical Characteristics and Quality of Life for Level of Injury Groupings	59
2.2.2 Correlation Coefficients for the Relationships between Fitness, Physical Activity and Subjective and Objective Quality of Life	60
2.2.3 Correlation Coefficients for the Relationships Between Physical Activity, Fitness and the Five Domains of Objective Quality of Life	65
2.2.4 Age, Duration of Injury and Quality of Life According to Fitness and Physical Activity Categories	68

List of Figures

Chapter 2.2 Determining the Relationship Between Quality of Life and Fitness and Physical Activity for Persons with Spinal Cord Injury

2.2.1 Quality of Life: Essential Components and Sub-components. The Centre for Health Promotion Model.	50
2.2.2 Scatter Diagram of Physical Activity vs. Objective Quality of Life (OQOL) for Individuals with High Quadriplegia	62
2.2.3 Scatter Diagram of Physical Activity vs. Objective Quality of Life (OQOL) for Individuals with Low Quadriplegia	63
2.2.4 Scatter Diagram of Physical Activity vs. Subjective Quality of Life (SQOL) for Individuals with Low Quadriplegia	64
2.2.5 Scatter Diagram of Physical Activity vs. Occupation Domain of Objective Quality of Life (OQOL) for Individuals with High Quadriplegia	66
2.2.6 Scatter Diagram of Fitness vs. Social Integration Domain of Objective Quality of Life (OQOL) for Individuals with Low Quadriplegia	67

CHAPTER ONE

1.1 Introduction

Persons with spinal cord injury are living longer than ever before because of improved medical care and better management of the health concerns directly related to spinal cord injury. Longitudinal investigations show that as the life span of this population increases, causes of mortality and morbidity move away from the traditional spinal cord injury related causes of death, such as kidney disease, and begin to parallel those of the able bodied population (Whiteneck et al., 1992). However, for the person with a spinal cord injury, illnesses that lead to deaths, still occur at an earlier age than would be expected in the general population (Whiteneck et al., 1992). Some researchers have shown a positive relationship between age and life satisfaction in spinal cord injured persons (Pentland et al., 1995; Post et al., 1998), though these findings have been inconsistent in the literature (Clayton & Chubon, 1994; Fuhrer et al., 1992). Nonetheless, as this population's life span increases it is necessary that research endeavours not only concentrate on reducing mortality and morbidity, but in finding ways to improve the quality of these individuals' lives (Shephard, 1997).

In able bodied populations, physical activity and fitness have been shown to reduce mortality as well as prevent coronary heart disease and diabetes (Heath & Fentem, 1997). Preliminary investigations have also shown that improved fitness levels have a positive impact on quality of life (Paffenberger et al., 1993). Traditionally, studies investigating the role of exercise in persons with spinal cord injury have addressed issues of fitness as it relates to health parameters and functional status. Greater fitness levels have been found to improve health parameters like high density lipoprotein (HDL-C)(Dallmeijer et al., 1997), and to improve functional status (Noreau et al., 1993). In addition, Stotts (1986) found that spinal cord injured persons who were active had a significant reduction in morbidity in comparison to inactive spinal cord injured persons. Subsequently, Reynolds (1993) reported that individuals with a spinal cord injury who

were actively involved in a personal exercise program, competitive sports, or recreational activities, not only had healthier bodies and a healthier outlook on life, but were also more active in vocational and educational activities. Clearly, there is evidence in the spinal cord injury literature to support a positive relationship between fitness and health factors. However, there is limited knowledge about the impact of physical activity on issues related to quality of life, such as employment and functional status. In addition, in spite of the importance of overall quality of life as an outcome measure (Lanig et al., 1996), there have been no investigations to date that have examined the impact of fitness and activity on overall quality of life in persons with a spinal cord injury.

The main objective of this investigation was to explore the relationship between quality of life and fitness and physical activity in persons with spinal cord injury. However, in order to address this issue, an appropriate quality of life measure for this population was needed. Quality of life for the spinal cord injured population has traditionally been represented by measures of health and function (Renwick & Friefeld, 1996) and inferences from those measures have then been made regarding the individual's quality of life. For instance, a person who is functionally more independent than another would be said to have better quality of life (Clayton & Chubon, 1994). However, this direct inference may not be appropriate as it has not been based on a conceptual model of quality of life (Renwick & Friefeld, 1996). Therefore, before the main research question could be addressed, the definition and representation of quality of life had to be explored more fully with the spinal cord injured population.

Thus, this thesis was comprised of two studies. The first study utilised a qualitative design in order to gain an understanding of the concept of quality of life for persons with a spinal cord injury. Through semi-structured interviews, individuals with spinal cord injury discussed the components that determined their quality of life. These findings were then used to assist in the selection of an appropriate quality of life questionnaire (if one was available) for this population.

With the information gathered from the first study and an appropriate quality of life questionnaire selected, the second study was undertaken. This study, which utilised both qualitative and quantitative methodologies, was designed to determine the relationship between fitness, leisure time physical activity and quality of life in

individuals with a spinal cord injury. The use of two different methodologies to answer the research question in Study Two was one way to accomplish triangulation. Triangulation is desirable as Lincoln and Guba (1985) suggest that it improves "the probability that findings and interpretations will be found credible" (p. 304).

1.1.1 Operational Definitions

- **Quadriplegia** – A term describing an injury to the spinal cord in the area of the cervical spine.
- **Paraplegia** – A term describing an injury to the spinal cord in the area of the thoracic, lumbar or sacral spine.
- **Subjective Quality of Life** – the composite representation of an individual's perception of their quality of life, as determined by scores on multiple dimensions of quality of life.
- **Objective Quality of Life** – the composite representation of objectively determined domains of quality of life. The five domains that have been used in this investigation to represent objective quality of life are: mobility, physical independence, occupation, social integration, economic self sufficiency. These domains are also the domains that represent level of handicap (World Health Organization, 1980) and thus the terms 'level of handicap' and 'objective quality of life' will be used interchangeably in this investigation.
- **Impairment** – refers to any loss or abnormality of psychological, physiological, or anatomical structure or function following a disease or an injury (World Health Organization, 1980)
- **Disability** –any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human (World Health Organization, 1980)
- **Handicap** – a disadvantage for a given individual that limits or prevents the fulfillment of a role that is normal (depending on age, sex and social and cultural factors) for that individual (World Health Organization, 1980)

- **Content Validity** – Content validity is normally assessed qualitatively by “determining the degree to which a measuring instrument or process contains tasks that inherently provide evidence about the traits or capabilities to be measured” (Hyllegard et al., 1996)
- **Construct Validity** – Construct validity is a representation of the degree to which a test actually measures the construct it purports to measure (i.e. quality of life). Construct validity is achieved using a combination of logical and statistical evidence.

1.2 Review of the Literature

1.2.1 Spinal Cord Injury Incidence and Causes

The incidence of spinal cord injury (SCI) is approximately 40 cases per 1,000,000 population annually in the province of Manitoba (Hu et al., 1996). These figures are comparable to incidence figures from the United States that report 30 to 40 cases per million population annually (Lanig et al., 1996). In Saskatchewan, the exact incidence rate of spinal cord injury is not known but there are currently about 500 persons in the province living with a spinal cord injury (North Saskatchewan Branch of the Canadian Paraplegic Association, personal communication, August, 1997). The provincial male-female distribution of about 75% male and 25% female closely parallels American statistics for spinal cord injured populations (Lanig et al., 1996). In addition, in the Saskatchewan population of spinal cord injured persons, about 40% have a quadriplegic injury while the remaining 60% have a paraplegic injury. These provincial statistics with regard to level of injury report slightly lower prevalence of quadriplegic injuries than American figures (Lanig et al., 1996).

Sixty one percent of those with a spinal cord injury are injured between the ages of 16-30 years (Buchanan & Nawoczenski, 1987). The most common cause of a spinal cord injury is motor vehicle accidents at 47.1% (Burney et al., 1992). Falls and acts of violence account for spinal cord injuries in 19.8% and 14.6% of cases, respectively. Other causes, such as recreational, sports and aircraft injuries account for 13.1% of spinal cord injuries (Buchanan & Nawoczenski, 1987; Burney et al., 1992).

1.2.2 Anatomy of the Spine and the Spinal Cord

The vertebral column is divided into cervical (C), thoracic (T), lumbar (L), sacral (S) and coccygeal regions (Buchanan & Nawoczinski, 1987). There are seven cervical vertebrae (C1-C7), twelve thoracic vertebrae (T1-T12), five lumbar vertebrae (L1-L5), five fused sacral vertebrae and four fused coccygeal vertebrae.

The spinal cord extends from the base of the brain to the level of the first or second lumbar vertebra (Freeman Somers, 1992). The cord is located in the vertebral canal and is protected anteriorly by the spinal vertebral bodies and laterally and posteriorly by the vertebral arches. The spinal cord can be divided into two principal units. The first is the local segmental unit that includes: a) incoming afferent fibres carrying somatosensory information about the local segment; b) neurons in the central spinal gray matter that control reflex and motor function of that segment; and c) outgoing motor fibres destined to innervate the musculature of the segment. The second unit contains the long sensory and motor tracts that travel in the white matter in the cord and carry information to and from the brain. An injury to the spinal cord at any level would cause disruption of neural functioning at that specific level but would also affect the transmission of information travelling along the tracts in the white matter (Mohr, 1989). One pair of spinal nerves, supplying the right and left sides of the body, is associated with each segment of the cervical, thoracic, lumbar and sacral regions. Each spinal nerve has a motor and sensory root corresponding to that vertebral segment (Freeman Somers, 1992). The coccygeal region has only one pair of spinal nerves. There are eight spinal nerves in the cervical region because from C1-C7 the spinal nerves exit the vertebral foramen above the correspondingly numbered vertebrae. The C8 spinal nerve exits below the C7 vertebrae. From C7 down all the spinal nerves exit below the correspondingly numbered vertebrae (Freeman Somers, 1992).

1.2.3 Classification of Spinal Cord Injury

An injury to the spinal cord can generally be characterised in two ways: 1) by the completeness of the injury, with the injury either being incomplete or complete and; 2) by

the level of the lesion. The American Spinal Injury Association (1992) defines an incomplete lesion as any lesion where sensory or voluntary motor function exists in regions supplied by segments of the cord more than three segments below the neurological level of the spinal cord injury. Thus, an incomplete lesion is characterised by some degree of preservation of motor and sensory function below the level of the lesion. A complete lesion of the spinal cord, in contrast, is characterised by a total lack of sensory and voluntary motor function below the level of the spinal cord lesion (Buchanan & Nawoczenski, 1987).

The level of the lesion is the other factor that describes a spinal cord injury and is reported by the region in which it occurs (cervical, thoracic, lumbar or sacral) and by the individual segment within that region. For example, a C5 injury indicates an injury where the last intact segment of the spinal cord is at the motor and sensory level of C5 (Maynard et al., 1997). Quadriplegia is the term that refers to an injury to the spinal cord between C1 and C8 spinal segments inclusive. A spinal cord injury with the last intact segment being T1 or lower is termed a paraplegic injury (Maynard et al., 1997).

Both the level of the lesion and the completeness of the injury impact on a person's functional ability. Functional abilities are most easily divided into three main categories: bed mobility, transfers and wheelchair mobility (Lyndhurst, 1995). Bed mobility refers to the individual's ability to move in bed and the ability to move from a lying to a sitting position. Bed mobility skills are required to progress into a position from which a transfer can be performed. A transfer refers to the means with which a person moves from one surface to another (i.e. bed to wheelchair, wheelchair to tub, wheelchair to car). The ability to move about the home and the community in a power or manual wheelchair is defined as wheelchair mobility.

Because of the varying degrees of motor and sensory preservation in persons with an incomplete spinal cord injury, their potential for functional independence can differ greatly from person to person (Lyndhurst, 1995). In comparison, functional abilities amongst individuals with complete injuries of the spinal cord are much more predictable. For instance, each person with a complete C7 quadriplegic injury will have intact musculature in a typical myotomal innervation and all will have similar potential for functional recovery. Potential for functional independence is, of course, affected by other

factors like age and secondary complications, but in general, persons with complete injuries at the same level of the spinal cord will have similar functional potential. Because of the greater homogeneity of the group of persons with a complete spinal cord injury, this current investigation focussed only on those individuals. The forthcoming section will discuss in more detail the ways in which the level of a complete lesion impacts on a person's functional abilities.

1.2.4 Functional Ability in Relation to Neurological Level of Injury

As mentioned previously, a quadriplegic injury is an injury involving the spinal cord between the levels of C1 and C8. As the level of the injury moves caudally in the cervical spinal cord, there is greater preservation of motor function distally. Therefore, the lower the injury in the spinal cord the greater the number of muscles innervated and thus greater potential for functional independence.

An injury that occurs between the levels of C1-C3 may render the affected person incapable of spontaneous breathing and that person will likely require ventilatory assistance (Buchanan & Nawoczenski, 1987; Zupan et al., 1997). The injury would also cause paralysis of voluntary musculature in all extremities and the trunk, as well as loss of sensation below the level of the head. A person with a spinal cord injury at C3 or above would be completely dependent on another person for all functional activities. Some individuals with injuries at C3 or above may have the potential to operate an adapted power wheelchair.

Individuals with a quadriplegic injury at the level of C4 would have the ability to breath spontaneously, however, their respiratory system would remain compromised. At this level, the diaphragm is not completely innervated and none of the trunk and accessory muscles that assist in coughing and secretion clearance are innervated (Zupan et al., 1997). A person with an injury at the level of C4 will have weak shoulder movement but no voluntary movement around the elbow joint. Again, these individuals would require total assistance from another person to accomplish bed mobility and transfers. They would however have the potential to use a head or chin control power wheelchair for mobility.

A person with a quadriplegic injury at the level of C5 will possess partial movement in all shoulder movements but muscle imbalances will be evident and result in a poorly stabilised shoulder girdle. In addition to innervation of the shoulder musculature, C5 is the first level where functional movement below the shoulder will be observed, including activity from the biceps and wrist extensor muscles (Lyndhurst, 1995). Persons with injuries at C5 will have the ability to feed themselves, unlike persons with injuries higher in the cervical cord. They may, however, require some adaptations for this activity such as universal cuffs or working splints for their hands. Bed mobility and transfers remain a dependent activity for persons with a C5 injury, however, a few exceptional persons may be able to transfer independently with the use of a device (i.e. headrest, sliding board) (Lyndhurst, 1995). Wheelchair mobility is accomplished with a hand driven power chair or lightweight manual chair, depending on the person's environment and motivation.

An injury at the level of C6 allows the affected person to achieve greater scapular and shoulder control and strong wrist extension (Freeman Somers, 1992). The biceps muscle at this level is now fully innervated, but muscle imbalances at the elbow exist because the triceps muscles are not yet functional. A person with an injury at the level of C6 would have the potential for independent bed mobility, and transfers may also become independent with much practice. Wheelchair mobility is usually accomplished in a manual wheelchair but if an individual's lifestyle demands greater energy expenditure, a power chair may be considered (Lyndhurst, 1995).

A person with a quadriplegic injury at the level of C7 will experience significant functional gains, in comparison with persons with higher levels of injury, because of the addition of the muscles that extend the elbow. There may also be partial innervation of wrist flexors and the thumb at this level. Most persons with a C7 quadriplegic injury have the potential to be independent with all bed mobility and transfers and a manual lightweight wheelchair would be used for mobility.

Whereas the individual who is quadriplegic has an injury between the levels of C1 and C8, an individual with an injury below the level of T1 inclusive is considered paraplegic (Lyndhurst, 1995). A person with a paraplegic injury would have complete upper extremity function and progressively greater innervation of trunk musculature as

the level of the injury moves lower in the spinal cord. At the level of L1, trunk musculature is fully innervated but there remains no voluntary movement in the lower extremities. All persons with paraplegia have the potential to be functionally independent with bed mobility, all types of transfers and wheelchair mobility.

1.2.5 Exercise Capabilities of Persons with Spinal Cord Injury

A central training effect with exercise is generally desirable for all persons because it leads to a more efficient cardiovascular system (i.e. decreased resting and sub-maximal heart rate, increased cardiac output), resulting in less stress on that system during activities of daily living. However, exercise response in persons with a spinal cord injury is generally limited by peripheral fatigue in the available working muscles, before the cardiovascular system has been stressed sufficiently to produce a central training effect (Figoni, 1993). Diminished venous return due to lower extremity muscle paralysis also contributes to the absence of central training effects seen with exercise in this population because it leads to venous pooling in the lower extremities and may result in ischemia in the active working muscles of the arms (Figoni, 1993).

While muscle paralysis limits the exercise response of all persons with a spinal cord injury, in general, as the extent of skeletal muscle paralysis increases, voluntary exercise capabilities and the potential for improvement in cardiopulmonary fitness levels decreases (Glaser, 1989). On a continuum of persons with spinal cord injury, those with the lowest injuries would have the greatest potential for improvement in fitness as they have the greatest amount of innervated muscle available. Those persons with higher levels of injuries have less potential for improvement in fitness because of less active muscle mass.

In addition to muscle paralysis, autonomic nervous system dysfunction in selected individuals with spinal cord injury also limits exercise capacity. Injuries to the spinal cord above the level of T6 are generally associated with some degree of autonomic dysfunction and all lesions in the cervical spinal cord result in significant impairment of the autonomic system (Davis, 1993). Cowell et al. (1986) contend that in paraplegics with injuries between the levels of T1-T4 inclusive there is potential for autonomic

dysfunction, however, it is generally accepted that autonomic nervous system dysfunction that limits exercise capacity could occur with an injury as low as T6 inclusive (Lanig et al., 1996). Sympathetic input from the autonomic nervous system is necessary for normal cardiovascular reflex responses to exercise. These responses include vasoconstriction in the non-exercising muscles, venoconstriction, vasodilation of skeletal muscle arterioles, increased heart rate, improved myocardial contractility and increased cardiac output (Glaser, 1989). With exercise in an individual with a high paraplegic or a quadriplegic injury, vasodilation of the vessels supplying the active arm muscles occurs, but there is no corresponding venoconstriction (due to sympathetic nervous system dysfunction) to facilitate venous return and maintain or increase cardiac output and stroke volume. In addition, maximum heart rate is usually limited to approximately 120 beats per minute in spinal cord injured individuals who have autonomic nervous system dysfunction.

This combination of decreased available muscle mass and autonomic dysfunction result in major exercise limitations for persons with quadriplegic or high paraplegic injuries. They will not be able to achieve as high a maximal aerobic capacity or maximal muscle power as persons with paraplegic injuries or able bodied persons (Coutts et al., 1983). Coutts et al. reported a significant difference in maximum power and maximum VO_2 (MVO_2) between three groups; quadriplegics, high paraplegics (T1-T6) and low paraplegics. MVO_2 was 0.97, 1.62 and 2.42 l/min respectively and maximal power was 24, 47 and 80W respectively. Hoffman, in 1986, summarised a number of investigations regarding spinal cord injury and exercise and found similar differences in MVO_2 between the selected groups.

The MVO_2 values reported by Coutts et al. (1983) indicate that the exercise capabilities of a person with a paraplegic injury are less limited than in a person with quadriplegia. This is a result of increased muscle mass (progressive addition of trunk musculature as the level of the injury moves lower) and less dysfunction of the autonomic nervous system (Lanig et al., 1996). Persons with a paraplegic injury below the level of T6 will have a normal heart rate response to exercise (Lanig et al., 1996; Martel et al., 1991; Noreau et al., 1993). In spite of this, cardiac output and stroke volume will be below normal for given levels of oxygen consumption when compared to the able bodied population. Hoffman (1986) reported that mean resting cardiac output for persons with

all levels of paraplegia was 75% of that of sedentary controls, and at maximal work loads, cardiac output was 68% of that of controls. This exercise response of reduced cardiac output for any given oxygen uptake is called circulatory hypokinesia (Davis, 1993) and is mainly due to diminished function of the venous pump which leads to venous pooling in the lower extremities.

Training effects for persons with spinal cord injury are most commonly peripheral, as opposed to central. Some evidence of central training effects, such as increased cardiac output and stroke volume, have been reported in a group of paraplegics with injuries at the level of T6 and below (Davis et al., 1991). However, there is no evidence to support the presence of a central training effect (characterised by changes in heart rate at rest and with sub-maximal exercise and changes in maximum cardiac output) in individuals with quadriplegia and high paraplegia when performing arm exercise in an upright position (Figoni, 1993). Thus, peripheral training effects are predominantly the effects seen in this population. Peripheral adaptations within the active arm muscle groups include muscle hypertrophy, increased energy stores, and increased localised strength and endurance (Lanig et al., 1996). In the absence of central training effects, peripheral adaptations are still valuable and can lead to improved work capacity and potentially increased strength (Lanig et al., 1996). In addition, it should be noted that maximal effort arm exercise tests with individuals with quadriplegia do not reflect the maximal exercise capacity of the central cardiovascular system. However, maximal exercise tests do reflect peak exercise capacity for that person within the physiological limits imposed by the spinal cord injury (Figoni, 1993).

1.2.6 Quality of Life and It's Measurement in Persons with a Spinal Cord Injury

Quality of life for able bodied persons has typically been described as a persons' satisfaction with various domains of life quality, including: 1) physical and material well being; 2) relations with other people; 3) social, community and civic activities; 4) personal development and fulfilment; and 5) recreation (Flanagan, 1982). The measurement of the quality of life of persons with spinal cord injury has traditionally used an objective approach (Dijkers, 1997). Dijkers described this approach as defining

quality of life as "the sum total of a person's scores on characteristics that can be objectively determined" (p.830). For the spinal cord injured population these characteristics might include things like income, health and functional status. Life quality for spinal cord injured persons has frequently been inferred from objective measures of health and/or functional status (Renwick & Friefeld, 1996). The functional status approach is concerned primarily with an individual's physical functional abilities, with a lesser focus on emotional and social function (Renwick & Friefeld, 1996). Examples of measures that use the functional approach to measure and then infer quality of life include the Barthel Index and Jette's Functional Status Index (Renwick & Friefeld, 1996). The health status approach to measuring quality of life is similar in that measures of health are collected and quality of life is inferred from that information. Examples of validated measures of general health status include the Sickness Impact Profile (Bergner et al., 1981) and the Short Form Health Survey (SF-36) (Ware & Sherbourne, 1992). It has been assumed that higher scores on these health and functional measures automatically reflected better quality of life. However, while it is recognised that health and functional status are likely related to quality of life, it is not appropriate to directly infer quality of life from those measures alone since they are not linked to well developed conceptual frameworks of quality of life (Renwick & Brown, 1996).

An important objective measure which was developed specifically for persons with a spinal cord injury is the Craig Handicap and Assessment Reporting Technique (CHART) (Whiteneck et al., 1992). This measurement tool gathers objective information about five domains related to quality of life: mobility, financial situation, social integration, physical independence and occupation. An objective score is then calculated for overall quality of life and the five individual objective domains it measures (Whiteneck et al., 1992). Though CHART has been shown to be a reliable and valid measure of objective quality of life, it has been suggested that the sole use of objective indicators to infer the subjective construct of quality of life may be inappropriate (Clayton & Chubon, 1994). Studies that have compared subjective quality of life with objective measures have reported discrepant results with regard to the relationships between objective and subjective indicators of quality of life. For example, Clayton and Chubon found that perceived quality of life was associated with educational level,

employment status, income and some social activities. In addition, these researchers observed that greater severity of disability was related to lower subjective quality of life scores. This latter finding was contrary to the work of Fuhrer et al. (1992), who found that life satisfaction was not related to objective measures of disability. Life satisfaction, however, was related to objective measures of social integration, occupation and mobility. In the last five to ten years it has become generally accepted that an objective measure of quality of life alone is not sufficient and that subjective perceptions and feelings must be included before overall quality of life can be reported (Fuhrer et al., 1992).

The subjective approach to the measurement of quality of life evaluates a person's current satisfaction with life and reflects the gap between an individual's aspirations and his current achievements (Noreau & Shephard, 1995). Subjective measures report this gap as it is perceived by the individual involved (Dijkers, 1997). Satisfaction with various quality of life domains like health, occupation, physical function and social integration, are typically included in subjective measures of quality of life (Clayton & Chubon, 1994). Some subjective questionnaires use a single item question to represent quality of life (Cushman & Hassett, 1992; Gerhart, 1991), while others ask more than 100 questions to arrive at a score for a person's quality of life (Rudman et al., 1995).

There are a number of subjective quality of life measures that are currently being used to evaluate the life quality of individuals with spinal cord injury. The instrument that has perhaps been used most often is the Life Satisfaction Index-A (Crisp, 1992; Fuhrer et al., 1992; Schulz & Decker, 1985). This measure was first used with the spinal cord injured population in a study which examined correlations between adjustment, social support and perceived control in 100 spinal cord injured men, who were 20 years post injury (Schulz & Decker, 1985). The Life Satisfaction Index -A (LSIA-A), however, is a scale that was originally developed for use with the elderly and as such, may have questionable validity for use with a spinal cord injured population (Krause & Crewe, 1991). In addition, there is no reported information about the validity of the scale with spinal cord injured persons (Schulz & Decker, 1985). The Life Situation Questionnaire (LSQ) is another example of a subjective questionnaire and was developed for a longitudinal study that examined adjustment and aging following spinal cord injury

(Krause, 1997). The third questionnaire used to evaluate the life quality of individuals with spinal cord injury is the Life Satisfaction Survey (LSS). This instrument has 20 questions, 10 that were developed empirically around 10 commonly accepted quality of life themes, as well as 10 items that were included after a critical incidents-based study of adults with a variety of chronic diseases or disabilities (Clayton & Chubon, 1994). The intent of the LSS was to provide a scale that would allow for a broad range of comparison studies with regards to life satisfaction (i.e. between disabled and/or non disabled populations) (Clayton & Chubon, 1994).

The above-mentioned quality of life measures currently in use for the spinal cord injured population are limited primarily because sufficient input is not being sought from spinal cord injured persons about what they feel contributes to their quality of life. Until more information about quality of life is available from persons with spinal cord injury, the validity of quality of life measures for this population cannot be confirmed. Dijkers (1997) concluded that there is limited information about what the determinants of quality of life are for persons with spinal cord injury and that further research is needed in this area. Currently, the subjective measures that are being used with this population have generally reported the person's subjective perceptions of quality of life domains that have been empirically determined by researchers and health care professionals. The limitation of this practice, however, is that researchers conduct studies which determine how satisfied individuals are with certain aspects of their lives before finding out which issues spinal cord injured persons believe are salient to the representation of their quality of life. Knowing something about satisfaction of one aspect of a person's life does not provide much useful information if that domain is not in fact important to that person. The individuals whose lives are being assessed must have greater input into the determination of which aspects of their lives will be considered relevant to the ultimate determination of their quality of life (Day & Jankey, 1996).

A methodology that provides participants with the opportunity to contribute important input is naturalistic inquiry. This technique allows participants to tell their own stories and cultivates the capacity to learn from others (Patton, 1990). Interviews with participants allow individual differences to be identified while at the same time indicate ways in which personal accounts of the participants may intersect. Rapheal (1996)

suggested that any quality of life measure should incorporate a component of qualitative inquiry because by nature, quality of life is an individual concept that is best understood by hearing about the individual's perspectives. In addition, naturalistic inquiry is important because it allows participants not only to identify the domains that are important to their quality of life, but also gives them the opportunity to explain why a particular domain is important (Dijkers, 1998). Understanding more about why domains are or are not important contributes valuable information to researchers in their endeavour to understand the concept of quality of life for this population.

To date, there are a limited number of qualitative studies that have gathered information about quality of life from persons with spinal cord injury, even though there is a need for research that allows the participants perspectives to be heard (Day & Jankey, 1996; Gill & Feinstein, 1994). Recently, two studies (Bach & McDaniel, 1993; Renwick & Brown, 1996) used naturalistic inquiry methodologies to address some of the past concerns about measurement validity and to improve our understanding of quality of life issues for this population. Bach and McDaniel (1993) conducted a focus group study with 14 individuals with quadriplegic spinal cord injury and reported several quality of life domains that were similar to those reported in the able bodied literature. Relationships, job and productivity, finances, health, inner strength/survival and level of activity were quality of life domains that were similar to those identified in the literature for the general population (Flanagan, 1982). In addition, the results of this investigation showed that assertiveness and dependence/independence were exclusive to the group of individuals with a quadriplegic injury (Bach & McDaniel, 1993).

In contrast to the work of Bach and McDaniel (1993), Renwick and Brown (1996) reported that the components representing life quality were similar for all persons, regardless of whether they were able bodied or disabled. The findings of Renwick and Brown were part of a larger quality of life project at the Centre for Health Promotion at the University of Toronto. The conceptual model used in the project describes quality of life for all persons as the sum total of three components: (1) being (who a person is as an individual); (2) belonging (how environments and others fit with a person); and (3) becoming (what a person does to achieve their hopes, goals and aspirations). In addition, two themes which emerged from qualitative interviews with disabled persons, as well as

able bodied persons, emphasised the importance of "the contribution of personal empowerment and choice to quality of life and the primary importance of individual's perspectives on their own quality of life" (Renwick & Brown, 1996, p. 76).

The investigations by Renwick and Brown (1996) and Bach and McDaniel (1993) provide preliminary information for the rehabilitation professional whose goal is to improve the quality of life of persons with a spinal cord injury. However, further research is warranted to attempt to replicate these findings and to investigate whether the issues related to quality of life for persons with a spinal cord injury vary according to the level of the injury. In addition, though the conceptual model of quality of life developed by Renwick and Brown is promising, it is relatively new and therefore requires further investigation to clarify the relationships in the model. To date, proponents of the Centre for Health Promotion model have examined relatively few numbers of persons with physical disabilities (less than 50) and further research with disabled populations is, thus, especially warranted. Gathering input about quality of life, from spinal cord injured persons themselves, will assist in the selection of an appropriate quality of life questionnaire for the second study in this thesis.

1.2.7 The Relationship Between Fitness, Physical Activity and Quality of Life

In recent years, health promotion programs that include exercise have tried to effect positive changes not only in traditional fitness parameters but also in the life quality of the participants. Yet, in spite of the belief that increased fitness and activity levels improve quality of life in spinal cord injured persons (Noreau & Shephard, 1995), these relationships have not been adequately explored, and there is little empirical evidence to support a relationship between the constructs.

Henderson and Bedini (1995) explored the experiences and meanings of physical activity for a group of women with mobility impairments using a qualitative methodology. Physical activity for the 16 women interviewed was represented by the following four themes: 1) physical activity as leisure; 2) physical activity as therapy; 3) physical activity as mental and physical maintenance; and 4) physical activity perceived as having little value (Henderson & Bedini, 1995). The first three themes represent areas

in which the participants felt physical activity benefited their lives. One participant commented on the value of physical activity for her and the difference between why able bodied persons exercise and why disabled persons exercise, "They do it to make them feel better. I do it to stay even"(p. 155). The last theme was included because there were also participants who felt that physical activity had little value in their lives or participants who felt that rest was more important to their health and well being than activity (Henderson & Bedini, 1995). In 1997, Stuijbergen and Rogers conducted a qualitative investigation with 20 individuals with multiple sclerosis and reported that physical activity and leisure was perceived to play an important role in the participants' quality of life. They stated that the benefits of activity were increased energy, maintenance of functional status and just "feeling better", both mentally and physically (Stuijbergen & Rogers, 1997). These two qualitative investigations provide interesting insights about the perceived value of physical activity to quality of life for a persons with a disability, however, only Henderson and Bedini interviewed any persons with spinal cord injury (three women out of the sample of 16). Clearly, there is much more that can be learned through qualitative methodologies about the relationship between physical activity and quality of life, especially as it relates to the spinal cord injured population. Morgan (1998) has suggested that qualitative inquiry is useful in supplementing quantitative information and providing possible explanations for those finding.

Quantitative investigations have also examined the impact of fitness and activity on selected parameters of interest which may be related to quality of life. Several studies have examined the relationships between physical activity and health parameters in spinal cord injured persons. Higher endurance capacity and sport participation have been found to be related to less frequent medical complications (Hjeltnes & Jansen, 1990) and fewer hospitalisations (Stotts, 1986). Stotts also reported that a group of wheelchair athletes had less serious medical complications related to kidney infections and skin breakdown than did the non athletic group. Hjeltnes and Jansen similarly reported that the rate of urinary tract infections was significantly reduced in the group of individuals with the highest oxygen uptake. Cross sectional investigations have found that spinal cord injured persons who are active in sports have higher high density lipoprotein-cholesterol (HDL-C) levels (Dallmeijer et al., 1997; Dearwater et al.,1986) and lower total cholesterol

(Janssen et al., 1997), which may reduce their risk of coronary heart disease. Additionally, Hooker and Wells (1989) demonstrated that a moderately intense eight week wheelchair ergometry training program elicited significant increases in HDL-C and decreases in triglycerides (TG) and low density lipoprotein cholesterol (LDL-C). In general, active persons with disabilities have fewer cardiac risk factors and a lower percentage of body fat than those sedentary individuals with a physical disability (Cowell et al., 1986). The above studies show that fitness improves objective markers of health in this population. A recent epidemiological investigation additionally found that quadriplegic persons with higher activity levels reported better self-rated health (Washburn & Hedrick, 1997).

Exercise has also been found to have a positive impact on physical function in spinal cord injured persons. Superior fitness levels have been correlated with improved functional status (e.g. transfers and wheeling) (Hjeltnes & Jansen, 1990), especially in a group of persons with quadriplegia (Noreau et al., 1993). Washburn and Hedrick (1997) reported that both paraplegic and quadriplegic persons who were inactive had significantly greater limitations in functional mobility than those persons who were more active. In addition, significant relationships have been found between decreased physical strain during activities of daily living and sport activity (Dallmeijer et al., 1996) and improved physical capacity (Janssen et al., 1994). This suggests that increased levels of physical fitness can improve functional abilities by decreasing the amount of effort required for individuals to perform their daily activities.

The relationship between vocation and physical activity has also been examined, albeit minimally, in the spinal cord injury literature. It has been suggested that persons who are active in regular exercise or sport programs are also more active in vocational and educational activities (Reynolds, 1993). Shephard (1991) proposed that the reason why greater fitness levels potentially allow spinal cord injured persons greater opportunities for employment is because those persons have fitness reserves for employment activities over and above what is required for the performance of activities of daily living. A study from Quebec lent support to this hypothesis when it found that a group of employed persons with paraplegia had lower body weight, lower body mass index and higher aerobic power than a group of unemployed persons with paraplegia

(Noreau & Shephard, 1992a). Curtis et al. (1986), however, found no correlation between employment status and sport participation.

The effect of physical activity on psychological well being including self esteem, self concept and stress has been studied frequently in able bodied populations. However, although there is a large body of literature about coping, adjustment and psychological well being following spinal cord injury, there is a paucity of information about any relationships those constructs may have with fitness and physical activity. Based on his work with other disabled groups, Shephard (1991) suggested that physical activity may reduce anxiety and depression, improve self concept, and counter stigmatisation of the disabled by demonstrating the potential of persons with disabilities. These statements are plausible, however, they have not been investigated adequately in the literature. The one investigation that examined the relationship between sports participation and the incidence of depression and anxiety in spinal cord injured persons found no significant difference between sports participants and non participants (Foreman et al., 1997).

In addition to possible psychological benefits, it is also reasonable to suggest that participation in sport and physical activity may have social benefits for the person with a spinal cord injury. Sport and physical activity provide opportunities to develop new friendships and form social support networks (Shephard, 1991). One investigation reported that spinal cord injured persons who perceived that they had some support from their community, had significantly fewer health problems than those who perceived they had little support (Anson et al., 1993). To date, however, the potential relationship between physical activity and social factors has not been examined in the spinal cord injury literature.

Results from previous research increase our understanding of the relationships between physical activity and parameters that may be related to quality of life, such as health, physical function and independence, emotional function, vocation and relationships and social function. All of these individual factors have been previously identified by Bach and McDaniel (1993) as domains that are important to the quality of life of persons with a spinal cord injury. However, one of the limitations of these past investigations has been the sole use of individual objective indicators of quality of life, with no attempt to include subjective indicators. Two previous studies (Clayton &

Chubon, 1994; Renwick & Brown, 1996) have emphasized that understanding the individual's subjective perception of his situation is essential in fully comprehending how the consequences of spinal cord injury affect each individual's quality of life. In spite of the importance of subjective indicators of quality of life, only one investigation (Washburn & Hedrick, 1997) has examined the relationship between physical activity and a subjective indicator of quality of life; perceived health status. The other studies (Curtis et al., 1986; Dallmeijer et al., 1996; Dallmeijer et al., 1997; Dearwater et al., 1986; Hjeltnes & Jansen, 1990; Janssen et al., 1994; Noreau et al., 1993; Noreau & Shephard, 1992; Stotts, 1986) have examined physical activity only as it relates to individual objective indicators of quality of life. For example, several studies have explored the relationships between physical activity and objective indicators of health (Dallmeijer et al., 1997; Dearwater et al., 1986; Hjeltnes & Jansen, 1990; Stotts, 1986).

Although the aforementioned investigations have provided information about individual indicators of quality of life, the role of physical activity in overall objective or subjective life quality of persons with spinal cord injury has not been determined. This is somewhat surprising given that quality of life has become an important outcome measure in determining the effectiveness of health promotion strategies (Lanig et al., 1996). A preliminary investigation by Cushman and Hassett (1992) found that global subjective quality of life was not related to involvement in exercise or recreational activities in a group of persons with spinal cord injury. However, a limitation of that study was the use of only a single question to determine perceived quality of life. In addition, fitness levels were determined exclusively through a mail in questionnaire.

Recent investigations have shown that physical activity is associated with health related quality of life in populations such as sedentary adults, persons with arthritis and the frail elderly (Rejeski et al., 1996). These findings have led to the speculation that similar relationships may exist in the spinal cord injured population. To date, however, this potential relationship has not been researched adequately. Important factors to consider when examining the relationships between activity and quality of life are the individual's chronological age and duration of spinal cord injury. In the past, investigations have shown superior life adjustment and better quality of life to be associated with both younger (Krause, 1998; Mehnert et al., 1990; Post et al., 1998;

Schulz & Decker, 1985) and older chronological age (Pentland et al., 1995). In addition, longer duration of injury or time since injury has been found to be associated with better adjustment and subjective quality of life (Krause & Crewe, 1991; Krause, 1998). Other researchers, however, have reported no relationship between these parameters (Fuhrer et al., 1992; Post et al., 1998). Krause and Crewe (1991) concluded that age and duration of injury tend to neutralise the effect of each other on life satisfaction. In other words, as persons age, their time since injury also increases, and thus the potential negative affects of age on life satisfaction are offset by the positive affects of increasing time since injury (Krause & Crewe, 1991; Krause, 1998). It is evident that the impact of age and duration of injury on quality of life has not been firmly established in the literature. However, it is possible that these variables may affect quality of life, and those relationships should be investigated. Therefore, in the second investigation, the relationships between age, duration of injury and the quality of life variables will be examined along with the primary relationships amongst the variables of physical activity, fitness and objective and subjective quality of life.

1.3 Statement of the Problem

1.3.1 Determining the Components of Quality of Life for Persons with Spinal Cord Injury

Quality of life measures are important outcome measures for health promotion strategies and rehabilitation programs for persons with spinal cord injury. However, because the domains that represent quality of life for the spinal cord injured population are not well understood, the validity of quality of life questionnaires for this population is questionable. Without validity, the important relationships between the effects of health promotion strategies like physical activity and fitness and quality of life cannot be understood. Increased knowledge of the spinal cord injured person's perspectives about the components of quality of life will provide essential information to assist in the establishment of content validity of quality of life questionnaires. In addition, it will be important to examine any differences that may arise between quadriplegic and paraplegic persons with respect to the representation of their quality of life. Previous qualitative investigations have not been afforded this opportunity because they interviewed persons

with a variety of physical disabilities (Renwick & Brown, 1996) or exclusively persons with quadriplegic injuries (Bach & McDaniel, 1993). Therefore, the objective of the first investigation in this thesis was to determine the components of quality of life for persons with quadriplegic and paraplegic spinal cord injuries.

1.3.2 Determining the Relationship between Fitness, Physical Activity and Quality of Life

In recent years, researchers have recognised that a positive change in quality of life is an important indicator of the success of health promotion strategies such as exercise (Lanig et al., 1996). Though previous investigations with spinal cord injured populations have shown fitness and physical activity to be positively correlated with individual objective measures of health, function and employment status, there have been few investigations that have explored the relationships between physical activity and global objective quality of life. In addition, in spite of the importance of subjective indicators of quality of life, there is very limited information in the literature about the relationship between fitness and physical activity and subjective quality of life. Therefore, the objective of this investigation was to determine the relationship of fitness and physical activity to overall subjective and objective quality of life in three groups of persons with a spinal cord injury: persons with high quadriplegia (C5 and C6), low quadriplegia (C7 and C8) and paraplegia. Examination of these groups, made up from the total sample, was important because of the differing potentials for exercise capacity associated with the different levels of injury (Hoffman, 1986; Noreau & Shephard, 1995). The relationship between objective and subjective quality of life was also explored in this thesis.

In this specific study, it was hypothesised that physical activity and fitness would be positively correlated with both quality of life measures. It was also hypothesised that the objective and subjective quality of life scores would be positively correlated with each other.

CHAPTER TWO

2.1 STUDY ONE: DETERMINING THE COMPONENTS OF QUALITY OF LIFE FOR PERSONS WITH A SPINAL CORD INJURY

2.1.1 Introduction

Health care professionals have traditionally focused on disability management and measurement when working with persons with a spinal cord injury (Whiteneck, 1994). Less attention has been directed to the evaluation of life quality, even though Wood-Dauphinee and Kuchler (1992) suggested that the overall goal of most rehabilitation professionals is to improve the quality of their patient's lives. Raeburn and Rootman (1996) stated that quality of life is a representation of how good life is for a person. In this respect, a change in life quality for a spinal cord injured person should be viewed as an important indicator of the effectiveness of health promotion strategies (Lanig et al., 1996).

Even though quality of life has become an important outcome measure, many of the measures currently in use have been developed for other populations or without input from persons with spinal cord injury. Thus, there may be limited evidence to support the validity of these measures with the spinal cord injured population. In order to evaluate the validity of such instruments, and to develop more valid instruments, researchers need to gain a better understanding from individuals with spinal cord injury of the various domains that should be included in the measurement of their life quality. Therefore, the objective of this qualitative investigation was to determine the domains that represent quality of life for persons with a spinal cord injury. By interviewing persons with both paraplegic and quadriplegic injuries, any differences related to level of injury, with respect to the representation of quality of life, will be identified.

2.1.2 Methods

Introduction and Design

This investigation utilised a qualitative research design to explore the concept of quality of life with spinal cord injured persons. Patton (1990) describes naturalistic inquiry as a process of studying real world situations as they unfold naturally. In naturalistic inquiry, the focus is on capturing process, documenting variations and exploring important individual differences in experiences (Patton, 1990). Qualitative methods permit the researcher to study selected issues, like quality of life, in depth and detail. Raphael (1996) suggested that use of qualitative methods is important to the assessment of quality of life, especially for disabled persons.

Participants

Purposive sampling technique was used in this investigation as it increased the range of data that could be uncovered (Lincoln & Guba, 1985). The sample was selected from a list of 150 persons with a complete spinal cord injury, between 3 to 30 years post injury, living within a 150 mile radius of the research institution. This list was generated from the Canadian Paraplegic Association (CPA) data-base. The research assistant and an individual from the CPA examined the list and selected individuals that were representative of different age groups, duration of injuries, gender and level of injury. Four individuals previously known to the research assistant were among the 15 persons selected. These individuals were then telephoned by a representative of the CPA and asked if they would consider volunteering for a study. If consent was given, the individuals were contacted by the research assistant and interview times were arranged.

Nine males and six females volunteered to be interviewed. The mean age of the participants was 36 years and age ranged from 22 to 63 years. Time since injury ranged from three to 36 years and the mean number of years since injury was 13. Seven persons had complete quadriplegic injuries (one female, six males) and eight persons had complete paraplegic injuries (five females, three males). Four of these persons lived in a

rural setting and the remaining 11 in an urban setting. Five participants were employed at least half time, two were in school full time and eight were unemployed.

Procedures

Approval from the University of Saskatchewan Ethics Committee was received before the study commenced. Semi-structured interviews were carried out by one person, a research assistant with six years experience working with the spinal cord injured population as a senior physical therapist. Prior to the interviews, the procedures were explained to each participant and an informed consent form was signed (Appendix 1).

Participants were interviewed individually in a quiet setting of their choice. The interviews were audio-taped and lasted approximately 45 to 60 minutes. Once introductions had taken place and rapport was established, participants were asked to talk generally about the things that were important to their life. They were also asked to discuss the ways in which the spinal cord injury had affected their life. Subsequently, they were questioned about whether the areas of their life affected by the spinal cord injury ultimately affected the areas that they had determined as important to their life. In closing, the participants were asked to define what the term quality of life meant to them. See Appendix 2 for semi-structured interview guide.

Data Analysis

Data analysis was an ongoing process from the initiation of data collection to the completion of the study. The data obtained during the project was interpreted and analysed using strategies suggested in the qualitative literature (Guba & Lincoln, 1981; Merriam, 1988; Patton, 1990). The goal of data analysis in qualitative inquiry is to find emerging themes in the data. This is achieved by identifying, coding and categorising patterns in the data.

At the conclusion of each interview the notes made during the interview were reviewed to determine emerging ideas and preliminary categories. These responses were recorded in the researcher's reflexive journal, a diary suggested by Lincoln and Guba

(1985). The interviews were then transcribed verbatim from the audio tapes and the manuscripts were reviewed several times by the research assistant and the principal investigator. While scanning the data, notes and comments were written on the manuscripts of the interviews to identify recurring thoughts and ideas of the participants. This information was cross referenced with the notes made in the researcher's reflexive journal. The process of unitising was then performed which involved working with the data to find units of information which came directly from the transcripts and included phrases, sentences or entire paragraphs.

The next stage of data analysis involved the formation of categories. The units of information gathered from the unitising process were grouped into provisional categories when the units seemed to relate to the same or similar content (Lincoln & Guba, 1985). In this investigation the file folder method was used (Bogdan & Biklen, 1982), as opposed to computer analysis, which generates categories and themes after units of information have been entered in the computer. The file folder method was chosen because it was felt that the manual process utilised in that method was, in this case, more effective in determining the themes than computer assistance. Following the placement of the similar units of information into the categorical file folders, the process of "looking for themes" began which involved finding a concept or recurring message that emerged from the data. The process of collapsing the categories into themes involved reading the content of the file folders and finding common ideas and concepts as well as the overall messages that were emerging.

Following preliminary identification of the quality of life themes, member checks were carried out. Lincoln and Guba (1985) stated that in naturalistic inquiry member checks are "...the most crucial technique for establishing credibility" (p.314). Member checks in this investigation consisted of distribution of a document that outlined the quality of life themes to persons that had been interviewed and to other stakeholders (i.e. employees at the CPA). Respondents were asked whether the documented themes captured what was discussed in the interviews. As well they were questioned about whether they felt that their quality of life could be represented in the themes. Some participants responded in writing while other member checks were accomplished through

discussion. Following the member checks and suggestions from the respondents, minor revisions and modifications to the quality of life themes were made.

Throughout the process of data analysis a "critical friend" was used to independently examine and audit the data findings and interpretations made by the researchers. Lincoln and Guba (1985) suggested that a critical friend should be a person who is similar in peer status to the principal investigator and somewhat familiar with the area of research. These guidelines were used to select the critical friend for this investigation. Once chosen, this individual is an important part of data analysis for a qualitative investigation as he or she serves to enhance the validity and dependability of the analysis (Lincoln & Guba, 1985). The critical friend determined if the findings were grounded in the data by following the audit trail from the raw data to the emergent themes. As suggested by Lincoln and Guba, the critical friend also looked at the analytical techniques used, the appropriateness of category labels and interpretations, and the possibility of alternatives. In order to perform the audit, the critical friend was given all the data collected in the pure form, as well as documentation regarding the decisions made throughout the study and the subsequent analysis.

2.1.3 Results

All of the participants in the study stated that quality of life was a subjective construct and as such, they were the only persons that could or should comment on their life quality. The respondents indicated that quality of life was what spinal cord injured persons themselves perceived it to be. One respondent described quality of life this way:

Basically doing what you want to do and enjoying it. I was thinking about quality of life, and you know it might look to a lot of people that there's not much going on in my life, but I like it.

Data analysis led to the establishment of nine themes which this group of spinal cord injured persons felt comprised their quality of life. These themes included: 1) physical function and independence; 2) accessibility; 3) emotional well being; 4) stigma; 5)

spontaneity; 6) relationships and social function; 7) occupation; 8) financial stability; and 9) physical well being.

Physical Function and Independence

Physical function and independence in this investigation represented a person's physical ability, which consisted of the participant's ability to transfer, perform bed mobility and wheelchair mobility, as well as his independence with activities of daily living. In general, the participants stated that it was very important to their quality of life to be as physically independent as possible within their limitations. One woman with a paraplegic injury stated:

Yeah, I try to be as independent as I can. My husband fixed up the lawn mower for me so I was able to cut the grass. This thing about having to wait on people to do it for you is really a burden. It really doesn't go well with me. So I try to find a way to do it or to have it set up so I can do it. Same with my yard, that's my goal after my house is built, is to set up my yard so I can totally look after it myself. I'm gonna fix it up so that nobody has to come out from town and do it.

An important aspect of physical function and independence was energy expenditure for everyday activities which was mentioned frequently by the participants as something that impacted their quality of life. The respondents stated that if a person could perform an activity independently, yet expended so much energy that they were unable to do anything else for the rest of the day, then that activity is not functional for that person and satisfaction in this domain would decrease. One participant discussed energy expenditure for daily activities in this way:

After all these years I still find it very frustrating to do some of the things that should be so simple yet they take so much energy. An incline that is a little too steep is just hard hard work to get up to the top. And yet if you're walking you'd take the stairs or the incline, I mean there is just nothing to it. I think a person in a wheelchair or whatever disability, expends a whole lot more energy, in relation to somebody who can just jump up and do this.

Accessibility

Accessibility (or lack of) affected the quality of life for many of the participants. One respondent with quadriplegia stated, " ...the environment is your barrier. If everything was set up for me perfectly then my quality of life would be absolutely wonderful. You know I could go anywhere I wanted and everything would be just perfect for me."

Seasonal accessibility was an issue for all of the participants. The respondents reported that cold temperatures and snowy sidewalks in winter made mobility and accessibility very difficult. One individual reported, "It's almost like come spring I get out of jail and I've been in jail for the last seven months and I haven't done a damn thing to be in jail, but I have been." Another participant discussed the difficulties related to accessibility that a spinal cord injured person faces when deciding whether to live in an urban or rural setting:

It's something that I still struggle with - how long I want to stay here [in the city]. But then I look at the issues that I think a lot of people with spinal cord injury look at, as far as being able to get out and get around independently. You don't have a choice. If I want to access a gym that's accessible with equipment, then I have to live in the city. If I want to go for a wheel at night I have to live in the city. I can't go wheeling down a gravel road, its just not practical. So its kind of a toss up.

All participants felt that accessibility was becoming less of an issue in recent years, although it still continued to be a factor that affected their quality of life. Throughout the interviews the participants reported that there were still many places that an able bodied person could access that they could not. For example, one women discussed how she was unable to get into the post office in her town because even though there was a ramp to the door, she couldn't get in the doors without help. Another discussed how he missed a lot of social opportunities because he couldn't access his friend's houses. The respondents also mentioned how ease of accessibility was a concern for them. Frequently the participants expressed frustration with the general population's lack of understanding with respect to this issue. One respondent stated:

I wish in this city before they built a ramp or did something that they'd have to get it approved by someone who's in a wheelchair, rather than just having a construction foreman say, 'well , there's your ramp'. Some of these boneheads don't have a clue.

Emotional Well Being

The theme of emotional well being was represented by two subcategories: 1) the participants' emotional health; and 2) the behaviours the participants engaged in which enhanced or detracted from their emotional health. The first subcategory represented the respondent's actual state of emotional health which included self esteem, self image and self confidence. Most participants reported that these issues affected their quality of life at some point in their adjustment to the spinal cord injury. As one individual stated, "you just don't feel whole sometimes."

Respondents also reported that at one time or another they had varying degrees of depression following their spinal cord injury which had affected their quality of life. One man talked about how he continued to feel depressed at times.

You dream. There are nights when I don't sleep good. I still fight depression sometimes, not every time but sometimes. Its not as often as it was but there are bouts of it that are just as bad as if it [the injury] just happened.

Some of the participants stated that depression negatively impacted their quality of life by making it difficult to get up in the morning and to find something to look forward to. Others, however, reported that while they may have been depressed following the injury, depression or depressive feelings were no longer as common or did not affect them at all. One young man who was injured when he was 15 reported that he now was just like everyone else, "You feel pretty down sometimes, but pretty much like everybody else. You get a bad day and you sit there and kind of mope. I don't really get depressed about anything any more." Another participant stated, "I'll tell you - I had good days and bad days when I was walking and I have good days and bad days now."

The second subcategory of emotional well being was made up of behaviours that impacted on the emotional well being of the participants. In the present study these behaviours were related to coping, adjustment and outlook following a spinal cord injury. This area was very important to the participant's quality of life as it was discussed frequently during the interviews. Many individuals were proud of how they had survived and enjoyed discussing their methods of coping. One participant with a quadriplegic injury described her recent experience at a job interview:

I don't tell people I'm in a wheelchair before an interview. They have no idea - that is the funniest thing but I don't think it's fair to me. So when I showed up at this interview they were just shocked. So I mean, I got the job on my own. That was good. That made me feel really good because I thought they're not thinking, well this girl, I don't know about her.

The coping methods which the respondents discussed during the interviews included possessing a sense of humour, not worrying about the things that can't be controlled, and the ability to recognise individual strengths and abilities. One respondent stated, "Yes, there are certain things that I know I just can't do and, it just comes to a point that it just doesn't bother you. You just can't let it bother you; that's the main thing - acceptance". Although the ability to accept one's injury was expressed by some of the participants, other persons reported that coping with the spinal cord injury was more of an adjustment to the disability as opposed to acceptance of that disability. This was expressed by one respondent who stated:

It's not that you accept it. People say you sure accept your disability but you know, it's not that I accept it, it's that I live with it and I do the best with what I have. I wouldn't say that I will ever accept it .

The participants who felt they were coping well stated that they were able to do so because of their efforts to adjust to the changes caused by a spinal cord injury. They reported they had found a way to appreciate what they were still able to do. One respondent who had a quadriplegic injury discussed how he coped with the spinal cord injury and overcame depression by recognising that there were others that were worse off than he was.

There was a women that had a heart attack or a stroke. She used to really make me so mad when I was in the hospital. My door was right at the buzzer and she'd drive her wheelchair up there and make that buzzer squawk, and she'd just sit there and they'd go and get her and bring her back, and she'd drag that chair up there again and sit there and make that buzzer squawk. And after about two weeks of that I thought, I can't walk and I can't do a heck of a lot but at least I ain't that mixed up, sitting there and making that buzzer squawk. And that really helped. She was kind of my saviour as far as my head because before that I was really depressed.

Other individuals who appeared to be having some difficulty coping with their injury frequently compared themselves to able bodied persons or to where they thought they should have been, had they remained able bodied. For example, one respondent stated "I really would have gone nuts if I couldn't drive. That's one thing I can do almost equivalent to anybody else... and in most circumstances it's pretty clear cut that you're not [equivalent]."

The respondents also stated that one's attitude and outlook were important factors related to a spinal cord injured person's quality of life. One participant demonstrated his positive attitude towards his injury when he said:

My thing is, its about five minutes slower than what I would be doing if I was walking. Like to go somewhere it would take me five minutes longer. So its not a huge change, I just get around with wheels. That's about it. Don't get the old feet working.

One respondent further stated, "I'm the same person that I was before the accident except that now I have to get around a little bit differently." The participants' positive outlook on life was evident when they discussed the things that they looked forward to and talked about their goals in life. One respondent talked about his goals of finding a career, "I look forward to trying to find some kind of career or something that I can do to contribute to society or whatever."

The majority of the participants also reported that they had somehow found the strength to find reason and purpose in their lives. Some individuals stated that their

quality of life had actually improved since the spinal cord injury as was evident in this quote:

The injury makes you think about what's important and what's not important. Before my injury a lot of things just really didn't concern me or I didn't think of them as big issues. Whereas after my injury, all of a sudden you had to, you learn to appreciate a lot of different things. It [the injury] tested me as a person. It makes you a little bit stronger I guess.

Many participants said that they had no choice but to adjust and carry on. A number of persons talked about how the spinal cord injury forced them into a personal growth they would not otherwise have achieved. It was apparent that emotional well being and the behaviours that one utilised to maintain or enhance it, were very important to overall quality of life.

Stigma

The theme stigma represented the perception that persons with a spinal cord injury have of other's attitudes toward them as a spinal cord injured person. The respondents stated that, if stigma was present or was perceived to be present, it had a negative effect on quality of life. The participants reported that stigma affected them to the greatest extent in the first 2-3 years after their injury. It then generally lessened over the years as they adjusted. One participant stated:

I really had a problem with that [stigma] when I was first injured. It's not so bad now that I had a baby because people don't look at me as being disabled. You know, she can have a baby or she can keep up her yard. People don't look at me like that around here because they know what I can do things and try before I'll say, 'no you better do it'.

The spinal cord injured person's reaction to stigma determined to a large extent how it affected their quality of life. One woman discussed people's attitudes and her changing reactions to them over the years:

It's really interesting, other people's perspectives. And I must admit, early on once I was back to work I found it very frustrating and quite demoralising in that lots of people seem to almost dismiss you. In that, oh well, if you're legs are paralysed, your brain must be too. That sort of thing drove me crazy. ...it doesn't happen nearly as often anymore. Probably because people are a lot more educated or whatever. But it was really tough to begin with. Like, you just wanted to go somewhere and cry. So it's interesting, that whole transition. Now I think, well, all people make mistakes. If some people haven't been around a person in a wheelchair, what do they know?

Some respondents also commented that they not only had to overcome the perceptions of others but also their own perception of people in wheelchairs; the perception that they held when they were able bodied. One respondent commented, "I don't seem to notice people notice the chair now. I mean I'm just who I am. It was probably that way ten years ago, except I perceived it to be different."

Spontaneity

Spontaneity (or lack of it) in all daily activities was frequently reported as something that affected the quality of life of the participants. The respondents stated that it took longer to do things and that much more planning was needed for all activities. One individual, when asked about how the spinal cord injury affected his life summed up the group's feelings about spontaneity when he stated:

Spontaneity. You have to plan a lot more. You can't just up and go wherever with whoever, whenever. There's gotta be some routine. Whether it's for personal care, whether it's for accessibility, whatever. I mean you might not be able to just up and go to the lake for the weekend if you need personal care, if you've got personal care staff coming in, or if it's not accessible and you don't have the transportation. So I think as far as where the spinal cord injury comes in, a big thing is the planning and the lack of spontaneity in a lot of situations.

Relationships and Socialization

The theme relationships and socialization included relationships with family, friends and significant others. Some of the participants reported that their relationships

with family actually improved following the spinal cord injury, as they no longer took them for granted. They came to recognise the importance of their relationships and cultivated them to a greater extent.

My family is a lot more important than they were. I mean, they were always important, but I depend on them more. Not as much as I did in the beginning, but just to know that I always know they're there. I just feel like they're more important.

The respondents, however, reported that forming new friendships and relationships with potential partners was more difficult now with a spinal cord injury. Some of the respondents made successful adjustments in this area, while for others this difficulty impacted negatively on their quality of life. One man discussed his lack of a relationship and how he felt it stemmed solely from the spinal cord injury.

I guess I can compare the situation I'm in now with where I should have been if I wouldn't have ended up in this thing [the wheelchair]. I would have been married, I would have had three kids and a dog or two. Things would have just been totally different than they are now.

Peer support was also identified as an important factor in the quality of life of a number of the participants in the sample. The respondents identified the Canadian Paraplegic Association, friends and associates in wheelchairs as being the major sources of peer support. One participant talked of the importance of support from peers and how it was easier for her to find such individuals in a bigger centre,

Actually I think the one thing I find about being in a smaller centre is I'm not around other people that are spinal cord injured and that's really hard. I mean it's not that they don't try to understand, but they can't. I think that's hard. Why I really like living in a larger centre, is that like I'm around my friends and stuff, because they know what it's like. If you have a bladder or bowel accident you don't have to explain it, they know. It's a comfort zone. They also know if you're out of shape what that means to your whole life. Whereas if you get out of shape if you're not disabled, you can still walk. So I think that being around people that understand or can relate to you is a really big part of it.

Occupation

Another quality of life theme that arose from the interviews was the importance of having an occupation. This included not only paid employment, but volunteer work, school and housework. One respondent described the importance of having a job in this way:

I don't know if having a job is more for financial reasons or if its just something to get you up and going. I was off for about 13 months and I just kind of hung around the house. You get pretty bored when you don't have much - you just get up and do nothing again all day. At least having a job makes you get up and gives you something to look forward to - even if you don't really like it some days.

Other participants felt that having an occupation was important because it had a positive effect on self worth and self esteem. One respondent reported that the sole reason she was looking for a job was for her self esteem. Because she didn't have a job like a lot of other women her age she felt it negatively affected feelings of self worth. The persons who were able to go back into the working environment they were in prior to their injury seemed to have an easier time adjusting than those who had to change their vocation, in addition to all the other changes caused by spinal cord injury.

Finances

All persons interviewed reported that their financial situation affected their quality of life. The respondents stated that health care costs and the price of equipment and services, like home care or housekeeping, were substantial. One participant discussed the issue of driving and how for some people it just wasn't an option because of the cost of the equipment needed:

Finances play a big part especially when you need a vehicle that's equipped. All that stuff costs money.... I've talked to a lot of people who say, 'well I would go and get my license, but I can't afford the vehicle and all that equipment'. It's the same for me. Having a vehicle makes you so much more independent. I would sell my left leg for that van.

The need for outside help to assist in the care of a person with a spinal cord injury can be costly in many situations. One man described one of the common problems a lot of families face when one member has a spinal cord injury. He discussed why his wife no longer worked, "she did for a while but that didn't make any sense. She was getting paid less than what we were paying them to look after me. What the hell's going on here?"

Lack of finances or financial difficulties were also noted to impact on leisure activities or simply the option to be involved in such activities. Respondents stated that for someone with a spinal cord injury, playing a sport or participating in a recreational activity was no longer simply a case of buying a pair of running shoes. One participant discussed these issues:

That's the thing with sports and stuff. I play in this chair [her everyday chair] but it gets banged up, and bumped out of whack and plus its just not set up to be a sports chair. Everyone else on my team has a rugby chair. I mean it's like you can't do the stuff you want to do without that modified equipment that costs much. So that's a big thing.

Physical Well Being

This theme encompassed two aspects of physical well being: (1) the participant's physical health and; (2) the behaviours and actions of the participants that promoted or detracted from their health. The first subcategory of this theme, physical health, represented the presence or absence of physical symptoms including physical illness, obesity or physical injury. The respondents reported that pain, spasticity, urinary tract infections and pressure sores were common health problems that had negatively affected their quality of life.

Health behaviours, in contrast to actual health, referred to what the respondents did to enhance or detract from their health. Participants discussed health behaviours such as eating a healthy diet, physical activity/recreation, and adequate rest as having a positive effect on their quality of life. They also discussed the importance of being proactive with regard to some of the common health problems related to spinal cord

injury. Some of these behaviours included pressure relief while up in the chair in order to avoid pressure sores and maintenance of a regular bowel and bladder regime so that infections could be prevented. One respondent also talked about physical activity as a health behaviour that played an important role in the prevention of obesity and in his quality of life.

I gain weight if I haven't been doing things and that tires me out more - I know it does. I get more sluggish and transfers get harder and I think its harder on the shoulders when I'm at a stage where I'm not doing things [exercising]. Yeah, I just feel better [with activity].

Another respondent talked about lifestyle choices and health behaviours, commenting on the potential they have to affect a person's physical health and function, and in turn, their quality of life.

Mostly I think its lifestyle things that impact our health. And, so it pays to pay attention to your lifestyle because, you're gonna pay for it sooner or later. So I mean eat properly so you don't get high cholesterol. Don't gain pounds and pounds and pounds, cause I know it would tire me out. I've seen quite obese people and I have no idea how they would get in and out of the wheelchair by themselves or in and out of a vehicle. I'm assuming pressure sores would be a problem with them also because there is that much more weight and pressure on your behind.

Physical well being was frequently discussed during the interviews and all participants felt that it had a big impact on their quality of life. Physical health was something that they were no longer able to take for granted, and as a result, many were very cognisant of it and anxious to learn more about the positive behaviours that may enhance their health.

Quality of Life: Paraplegia vs. Quadriplegia

The results from the present study showed that, regardless of the severity of the impairments, individuals with a spinal cord injury felt that their quality of life consisted of nine domains: 1) physical function and independence; 2) accessibility; 3) emotional

well being; 4) stigma; 5) spontaneity; 6) relationships and social function; 7) occupation; 8) financial stability and; 9) physical well being. Although the issues representing quality of life were similar for both quadriplegic and paraplegic individuals, it was apparent that two of the themes, physical function and independence and physical well being, affected the life quality of a person with a quadriplegic injury to a greater extent. Hand function was specifically identified as decreasing physical function for persons with quadriplegia. This limited function had implications for: 1) writing in school and work settings; 2) mobility in terms of opening doors and wheeling; and 3) activities of daily living like eating and grooming. Respondents with a quadriplegic injury stated that they frequently required adaptive equipment and that tasks usually took more time and effort than for a person with a paraplegic injury.

Physical well being was the other domain that affected those with a quadriplegic spinal cord injury more so than the paraplegic group. The most common example of this discrepancy was in relation to body weight. The importance of maintaining an optimal body weight was frequently discussed by both persons with quadriplegia and persons with paraplegia with respect to the effect it could have on a person's overall health and function. However, it was apparent that the group of persons with quadriplegia had to work harder in terms of nutrition and physical activity (health promoting behaviours) in order to maintain an optimal body weight.

2.1.4 Discussion

The objective of this study was to determine the domains which represented quality of life for persons with a spinal cord injury. The results showed that, regardless of the severity of the impairments, life quality encompassed nine areas: physical function and independence, accessibility, emotional well being, stigma, spontaneity, relationships and socialization, occupation, finances, and physical well being. Since persons with both paraplegic and quadriplegic spinal cord injuries live their life from a wheelchair and thus deal with common issues, it was not unexpected that the quality of life domains were similar between the two level of injury groups. Although all of the participants identified the same parameters encompassing quality of life, the results further showed that the

domains of physical function and independence and physical well being had a greater impact on the life quality of persons with a quadriplegic injury. This may be explained by the work of Bauman and Spungen (1994) and Noreau et al. (1993) which showed that a quadriplegic injury has more serious implications for a person's health and function than does a paraplegic injury. In addition, since a person with a quadriplegic injury typically expends more energy performing activities of daily living than a person with a paraplegic injury (Janssen et al., 1994), this would also impact their physical function to a greater extent.

The findings additionally showed that satisfaction (or lack of) in one or more of the domains of quality of life often had an effect on other domains. For example, respondents stated that manifestations of ill health, such as pain, often had a negative effect on the domain of physical function and independence. In some cases an increase in pain meant that a greater amount of effort was required in performing activities such as transferring into a car or onto the bed. For other participants, pain led to the loss of independence in functional activities. The results also showed that the domains of physical well being and socialization tended to affect one another as well. Participants reported that frequent bladder infections and pressure sores directly affected the social aspect of their quality of life because they were at times too sick to go out or were limited in the amount of time they could be in their wheelchair. Respondents also stated that financial difficulties often led to dissatisfaction in the physical well being domain. Financial problems could mean that a person had to use a wheelchair that was considerably heavier than the newer lightweight, more expensive wheelchairs. The use of a heavier wheelchair has the potential to negatively affect mobility and would invariably increase fatigue and risk of injury (e.g. pulling a heavy wheelchair into the car), thereby decreasing satisfaction in the physical well being domain. These examples illustrate that the themes related to quality of life do not necessarily represent themselves in isolation but may have a significant impact on other areas of the life quality of an individual.

In the past, the evaluation of life quality for persons with a spinal cord injury has been based upon parameters for healthy persons or older adults (Bach & McDaniel, 1993). Recent qualitative investigations have reported mixed results when determining

whether similar quality of life parameters apply for all populations. Renwick and Brown (1996) found that quality of life for an individual with a spinal cord injury could be evaluated using the same conceptual framework for all people. The work by Bach and McDaniel, however, which showed that some quality of life domains were exclusive to the spinal cord injured population, would suggest that using measures based on work with other populations may not be valid. In the present study the domains of emotional and physical well being, relationships and socialisation, occupation and finances were also identified by Renwick and Brown and Bach and McDaniel as factors important to the life quality of physically disabled persons. These domains have also been found to be significant factors in the representation of quality of life for able bodied populations (Flanagan, 1982). Although there has been general consensus in the literature that these domains are important to quality of life for all persons, satisfaction in some domains associated with work, finances, health and social relationships has generally been lower for the spinal cord injured population (Dijkers, 1997). This may be due in part to the stigma and problems associated with mobility and accessibility that were evident in the present study. Overcoming the real or perceived barriers of stigma, as well as the limitations of accessibility and mobility, may make it difficult to find employment and to be proactive with regard to health concerns related to the physical disability. In addition, even in a country with a universal health care system, there are financial burdens that are incurred by the person with the spinal cord injury and their family in order to fulfil the health needs of the spinal cord injured person. These findings suggest that even though there are several quality of life domains that are similar between able bodied and spinal cord injured persons, some of these domains may have a greater impact on the quality of life of the spinal cord injured population.

The results also identified four domains of quality of life for the spinal cord injured population; accessibility, stigma, spontaneity and health promoting behaviours, that have not typically been included as components for the able bodied person (Flanagan, 1982). In addition, these components have not been identified previously as quality of life domains for persons with a spinal cord injury (Bach & McDaniel, 1993; Renwick & Brown, 1996). Renwick and Brown, however, did identify the issue of accessibility as an important part of an individual's physical belonging within the

environment and with others. Even though most participants in the current study agreed that accessibility was improving and that stigma was decreasing, the respondents reported that these issues continued to affect their quality of life. This finding was reinforced by Renwick and Friefeld (1996) who stated that, "environmental factors (e.g. social, political, cultural and physical) continue to pose significant obstacles to their [persons with disabilities] opportunities for participating in and contributing to society" (p. 28-29). Spontaneity was another quality of life theme that was frequently discussed by our participants. Stensman (1994) similarly reported that one of the negative effects of a spinal cord injury was, "not being able to do things 'at once'" (p. 420). Adjustment to this change determined to a large extent how quality of life was impacted for the participants in the present study. Some were well adjusted and reported that lack of spontaneity was just a 'fact of life'. Nevertheless, while spontaneity has been cited previously in the spinal cord injury literature, it is not a factor in the representation of an able bodied person's quality of life.

Health promoting activities or behaviours can be defined as "activities directed toward increasing the level of well being and actualising the health potential of individuals" (Stuifbergen & Rogers, 1997, p. 2). Though this theme has not been specifically identified in the past as being an important quality of life domain for able bodied persons (Flanagan, 1982) or for those with a spinal cord injury (Bach & McDaniel, 1993; Clayton & Chubon, 1994), Flanagan and Renwick and Brown (1996) do recognise recreation and leisure as a part of quality of life. Similar to the present investigation, a recent qualitative investigation with a group of person's with multiple sclerosis identified physical and emotional health promoting behaviours as important to that population's representation of quality of life (Stuifbergen & Rogers, 1997). Participants in that investigation reported that they needed to be more careful to maximise their physical and mental capabilities since their health status was already vulnerable (Stuifbergen & Rogers, 1997). The participants in the present study also expressed similar sentiments when discussing why health promotion behaviours, both physical and emotional, were important to their quality of life.

The results from the present investigation support the findings of earlier investigations regarding the components which represent quality of life for the spinal

cord injured population. It also introduces other domains important to the life quality of this population that were not previously reported. The use of qualitative methodologies in this study allowed these domains to be identified and also provided the opportunity to recognise areas where the domains crossed over and affected one another. Identification of these crossover effects potentially improved our overall understanding of how a spinal cord injury affects a person's life. In addition, recognising the reasons for a lack of satisfaction in specific quality of life domains is important to the development of programs that address and attempt to remedy the problems.

The findings from this investigation also reinforce the theory that quality of life should be represented by subjective measures, if not totally, at least in combination with objective measures (Rapheal, 1996). Qualitative information that reveals the spinal cord injured population's views about what is important to their quality of life can assist in the appropriate selection of a quality of life measurement tool and help establish the validity of that chosen measure. By increasing our knowledge about what is important to the quality of life of a person with a spinal cord injury, the results of this investigation can provide a basis for the development and implementation of programs for spinal cord injured populations aimed at enhancing quality of life.

2.2 STUDY TWO: DETERMINING THE RELATIONSHIP BETWEEN QUALITY OF LIFE AND FITNESS AND PHYSICAL ACTIVITY FOR PERSONS WITH A SPINAL CORD INJURY

2.2.1 Introduction

Quality of life has increasingly become a key outcome when determining the success of rehabilitation programs for persons with spinal cord injury (Lanig et al., 1996). Health promotion strategies for the spinal cord injured population have included fitness and activity programs and researchers have suggested that those interventions may improve quality of life (Noreau & Shephard, 1995). However, traditional quantitative investigations with regard to exercise in spinal cord injured persons have focussed primarily on changes in physiological parameters like maximal oxygen consumption (MVO_2) or maximum muscle power with an exercise program (Hoffman, 1986). These investigations show that exercise parameters can be improved with training in persons with most levels of spinal cord injury (Hoffman, 1986). Recent investigations have also suggested that improved fitness can lead to improved health and function in spinal cord injured persons (Noreau et al., 1993). However, to date, the role that fitness and activity may play in a spinal cord injured individual's overall quality of life is not well understood.

In the past, overall or global quality of life has been represented in three ways, as: 1) objective quality of life; 2) subjective quality of life; and 3) health related quality of life. An overall objective quality of life score can be determined by summing an individual's scores on domains of quality of life that can be objectively determined, such as health, function and finances. Subjective quality of life, in contrast, refers to an individual's satisfaction with various quality of life domains, which may include health and function but may also include happiness, satisfaction with living situation or satisfaction with finances (Rejeski et al., 1996). Overall subjective quality of life would then be determined by the summation of the scores of the domains of subjective quality of life. Some investigations, however, report overall subjective quality of life simply as the score of a single question, "how would you rate your quality of life?" (Cushman &

Hassett, 1992; Gerhart, 1991). Health related quality of life is also a subjective measure of quality of life but is restricted to the individual's subjective appraisal of function, primarily physical, emotional and intellectual (Rejeski et al., 1996). Therefore, health related quality of life measures would exclude an indicator of satisfaction with finances, an area that may be included in global subjective quality of life. An improvement in any of these three indicators has been viewed as evidence of the success of a health promotion strategy (Lanig et al., 1996). However, there is little known about the relationship fitness and physical activity may have with quality of life in the spinal cord injured population.

Therefore, the objective of this investigation was to explore the relationships amongst the variables of fitness, physical activity and subjective and objective quality of life in persons with spinal cord injury.

2.2.2 Methods

Introduction and Design

Both qualitative and quantitative methods were utilised to address the research question in Study Two. Qualitative data collection, used to determine the relationship between fitness, activity and quality of life, was completed in conjunction (i.e. at the same time, in the same interviews) with the earlier investigation in this thesis that determined the components of quality of life for spinal cord injured persons. Issues related to physical activity were addressed in the interviews after considerable discussion about the components of quality of life. This allowed the participants to discuss the impact of physical activity in relation to the domains they had indicated were important to their life quality. If persons described themselves as inactive we also discussed why that was so and whether that lack of activity had impacted on their life either positively or negatively. Please see Chapter 2.1.2 for description of the participants, procedures and data analysis for the qualitative portion of the investigation.

Only the methods for the quantitative portion of the present investigation will be described in detail in this section. The quantitative portion of this investigation utilised a

cross sectional, exploratory research design to examine the relationship between fitness, activity and quality of life in spinal cord injured persons.

Participants

Forty participants were recruited for this investigation with the assistance of the Rehabilitation Centre at Saskatoon City Hospital and the Canadian Paraplegic Association. A letter asking for voluntary participation was sent through the Canadian Paraplegic Association to approximately 160 identified persons with a spinal cord injury, living within a 150 mile radius of the testing site, whose time since injury ranged from greater than 2 to less than 30 years. Persons with a spinal cord injury less than two years duration were excluded because quality of life has been found to be an unstable construct until at least two years post injury (Stensman, 1994). In addition, participants were excluded if their primary mode of locomotion was not a wheelchair (i.e. an incomplete spinal cord injury). Persons that replied and volunteered to participate were contacted by the research assistant for this investigation and the procedures were discussed in more detail. At that time, the research assistant also ensured that the participants met the criteria for inclusion, as mentioned above. If all the criteria were met, an appointment time was arranged for testing.

The participants were characterised by the following descriptors: chronological age, duration of injury (number of years since injury), level of injury (high quadriplegic, low quadriplegic, paraplegic), height, weight and present physical activity level. Age and duration of injury were determined prior to the person's inclusion in the sample and confirmed with participants when they arrived for testing.

Following data collection, participants were grouped according to their fitness and physical activity levels (high and low fitness and high and low active). Classification was done such that where possible, equal representation of level of injury (i.e. high quadriplegia, low quadriplegia and paraplegia) and gender (i.e. male and female) was achieved in each fitness (i.e. high and low) and activity (i.e. high and low) group. Within the level of injury and gender groupings, participants were ranked according the method outlined by Noreau et al. (1993) who examined the relationships between physical

activity and function in spinal cord injured persons. Classification of participants in this manner was necessary so that level of injury and gender would not confound the comparisons between the fitness and physical activity groupings.

Procedures

Approval to conduct this investigation was received from the University of Saskatchewan Ethics Committee prior to the initiation of the study. Participants completed consent forms and were screened for the presence of absolute and relative contraindications to an exercise test by a physical therapist. They were questioned about any difficulties with their heart including history of chest pain, previous abnormal ECG, arrhythmias as well as blood pressure abnormalities and diabetes (American College of Sports Medicine, 1995). If a participant demonstrated any of these risk factors, a physician was contacted to discuss administration of a maximal exercise test with that participant. Potential risks or side effects were discussed with the participants and they were informed that short term fatigue may occur following the exercise test. The consent form (Appendix 3) clearly indicated that the subject was free to withdraw at any time and that any information gathered would be kept completely confidential. After receiving informed consent, the following information and measures were obtained from each participant.

Demographic Information

Participants completed a questionnaire (Appendix 4) that included information about marital status, educational level, employment status, past medical history (including current medications) as well as birth date and date of spinal cord injury. At the testing site, a physical therapist checked the background information and asked for confirmation and clarification of information, especially medical history. Participants were asked about any missing information, as noted by the research assistants, and the participants were requested to fill in that information when able.

Physical Measures

Height was measured using the arm span method. With the subjects sitting, they were asked to spread their arms out to their sides with elbows, wrists and fingers straight and shoulders abducted 90 degrees. If the subject was unable to voluntarily perform any of those tasks, manual assistance was provided. Measurement to the nearest 0.1 centimetre was taken anteriorly across the person's chest from the tip of the right hand third digit to the left hand third digit. Two persons took the measurements while a third individual observed to ensure proper technique was used. The third person also assisted with maintenance of an erect sitting posture. Two measurements were taken initially. If the measurements were within two centimetres of each other, the mean was used to represent arm span. If the two measurements were greater than two centimetres apart a third measurement was taken and the median was used to represent arm span. The Sensormedics conversion formula was then used to convert the arm span measurement into height. This method of measuring height has been found to be reliable and valid for use with disabled populations (Garshick et al., 1997; Jarzem & Gledhill, 1993).

Weight was measured to the nearest 0.1 kilogram using a Toledo platform weigh scale. The participants transferred (either independently or with assistance) onto a seat on the platform where the total weight was recorded. The participant's weight was calculated by subtracting the weight of the seat from the total weight. It was not reasonable to have each person transfer onto the seat twice, therefore weight was only measured once. For one subject who was very heavy, the most recent weight from the hospital (one month prior) was used. Body mass index (BMI) was calculated for each individual, using the formula: $BMI = \text{weight (kilograms)} / \text{height}^2 \text{ (meters)}$.

The level of spinal cord injury of each individual participant was determined by a physical therapist through myotomal and dermatomal testing. The American Spinal Injury Association (ASIA) system for classification of spinal cord injury was used to categorise the participants as either a person with quadriplegia (high or low) or a person with paraplegia (Maynard et al., 1997). Persons with high quadriplegia were characterised as those individuals with an injury at the spinal cord level of C5 and C6. Participants with low quadriplegic injuries were those with injuries at the level of C7 and

C8. Finally, individuals with injuries classified as paraplegic were all persons with spinal cord injuries below the level of T1 (inclusive).

Measure of Subjective Quality of Life

The questionnaire used to measure the subjective quality of life of the spinal cord injured individuals participating in this investigation was the Quality of Life Profile: Physical and Sensory Disabilities Version (QOLP-PSD) from the Centre of Health Promotion at the University of Toronto (Rudman et al., 1995). The use of QOLP-PSD as the measurement tool for subjective quality of life for this investigation was justified based on the results from the qualitative investigation reported in Study One (Chapter 2.1). These findings, which identified nine domains as being important to the quality of life of persons with spinal cord injury, are successfully captured in the QOLP-PSD. The QOLP-PSD especially addresses the specific issues of accessibility, stigma and health promoting behaviours; issues that are not well addressed in other questionnaires. In addition, the QOLP-PSD records the individual's perceptions of their functioning in each of the domains, as opposed to recording objective markers of that function. This was an important aspect in choosing this measurement tool as participants in the qualitative investigation from Study One strongly believed that quality of life was a subjective construct and thus should be represented as such.

The Centre for Health Promotion defines quality of life as " the degree to which the person enjoys the important possibilities in his or her life", with ' possibilities' referring to the opportunities and constraints in people's lives as well as the balance between them (Renwick & Brown, 1996, p. 80). The Centre for Health Promotion's conceptual framework focuses on the person's possibilities in three fundamental areas of life. An underlying assumption of this framework is that these three fundamental areas related to quality of life are common to all persons, regardless of disability. The areas that comprise quality of life include: 1) being (who a person is as an individual); 2) belonging (how environments and others fit with a person); and 3) becoming (what a person does to achieve their hopes, goals and aspirations) (Renwick & Brown, 1996). See Figure 2.2.1 for illustration of the Centre for Health Promotion model of quality of

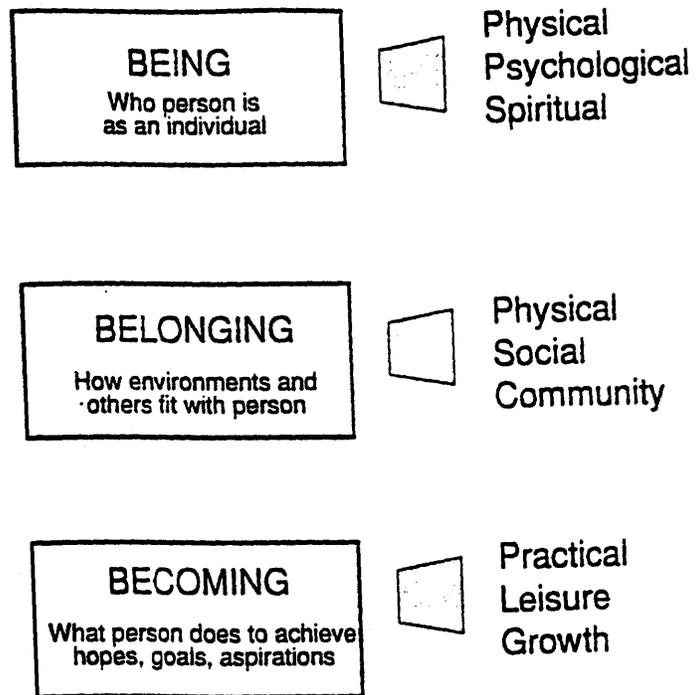


Figure 2.2.1
Quality of Life: Essential Components and Sub-components. The Centre for Health Promotion Model.

life. From these three areas and input from qualitative interviews with various populations including able bodied, physically disabled and elderly, a generic quality of life questionnaire was developed. Further interviews were then conducted with persons who were physically disabled so that the generic questionnaire could be modified for that specific population. Issues related to independence and accessibility were noted to affect quality of life only with the disabled population (R. Renwick, personal communication, July 24, 1997). As a result, items were added to the Quality of Life Profile: Physical and Sensory Disabilities version (QOLP-PSD), by the authors, to address these concerns.

The three components of the questionnaire (being, belonging, becoming) are further subdivided into three sub categories that serve to represent each component. The subcategories that represent the first component, 'being', are: 1) my body and my health; 2) my thoughts and feelings; and 3) my beliefs and values. 'Belonging' is represented by the subcategories of: 1) where I live and spend my time; 2) the people around me; and 3) my access to things in the community. The last component, 'becoming', is comprised of: 1) the practical things I do; 2) the things I do for fun and enjoyment; and 3) the things I do to cope and change. Each of the nine subcategories has between 9 and 13 items that represent it. See Appendix 5 for QOLP-PSD.

The QOLP-PSD is organised so that it asks first about how important every item in the subcategories is to the person and then about the person's satisfaction with that particular item. Each item is scored on a scale of 1 to 5, with 1 being not at all important (or satisfied) and 5 being extremely important (or satisfied) (Renwick & Brown, 1996). The final score for each individual item is computed from the importance and satisfaction scores and equals: (Importance score) X (Satisfaction score-3). The final score for each item therefore ranges from -10 to 10. A score for each of the nine subcategories is determined by summing the scores of the items in that subcategory. It is possible using the QOLP-PSD to arrive at a score for each of the subcategories as well as a composite score for quality of life. A composite score can be determined by summing all the scores from the subcategories, with higher scores indicating better quality of life. The Centre for Health Promotion is working on developing normative data for physically disabled populations but at present there are no norms available for comparison (R. Renwick, personal communication, July 24, 1997).

The last two sections in the questionnaire address the control and the opportunity (or lack of) a person feels he has over the nine areas (subcategories) of their life. The scores on the control and opportunity items do not figure into the actual scores for each subcategory or the composite quality of life score. They do, however, serve to explain some of the quality of life scores as they have been found to act as moderating factors (R. Renwick, personal communication, July 24, 1997).

Examination of 27 physically disabled individuals' responses using the QOLP-PSD resulted in an internal consistency (alpha coefficients) of the overall quality of life score of 0.97, while the internal consistency of the importance and satisfaction scores were 0.96 and 0.98 respectively (Rudman et al., 1995). Construct validity was examined in comparison with two subjective scales; the Satisfaction with Life Scale (Deiner, 1984) and the Memorial University of Newfoundland Scale of Happiness (Kozma & Stones, 1991). Correlation between the QOLP-PSD and the Deiner scale was $r=.2875$ ($p=.07$) and the correlation between the QOLP-PSD and the Kozma scale was $r=.4426$ ($p<.01$). The researchers at the Centre for Health Promotion were satisfied with the strength of these correlation coefficients as they felt that they indicated that the QOLP-PSD tapped into some of the same constructs but did not totally overlap them. They concluded that the QOLP-PSD represents the quality of life construct in a different way and that it may provide a more comprehensive depiction of quality of life than the other two scales (R. Renwick, personal communication, August 6, 1997).

In the present investigation, the participants filled out the QOLP-PSD individually (without the assistance of family members) at the testing site. Research assistants were available to answer questions as necessary. If the participant did not have sufficient hand function to write the answers, a research assistant wrote for them.

Measure of Objective Quality of Life

The Craig Handicap Assessment and Reporting Technique (CHART) is a self-administered questionnaire that was sent to the participants to fill out at home prior to exercise testing. At the testing site, the questionnaire was examined by the research assistants for completeness and the participants were asked if they had any problems with

interpretation of any of the questions. Any problems were then addressed by the research assistants and participants together.

CHART is a composite measure of handicap that was developed for the spinal cord injured population (Whiteneck et al., 1992a). Because Whiteneck and colleagues have indicated that CHART may be used to measure the objective component of quality of life, in this present investigation the term 'level of handicap' will be used synonymously with the term 'objective quality of life'. Handicap is defined as the disadvantage for a given individual that limits or prevents the fulfilment of a role that is normal for that individual (World Health Organisation, 1980). Thus, the goal of CHART is to measure deviations from roles generally fulfilled by able bodied members of society. It measures five objective domains related to quality of life including: mobility, economic self sufficiency, social integration, physical independence and occupation. An individual score for each domain is reported as well as a total CHART score that is the sum of all the domain scores. Higher scores indicate better objective quality of life and less handicap. The test retest reliability value of the overall CHART score was found to be 0.93 in a sample of 135 individuals with spinal cord injury (Whiteneck et al., 1992a).

Whiteneck et al. (1992a) examined the validity of CHART with the assistance of rehabilitation professionals who were well acquainted with the persons in the sample. The rehabilitation professionals were asked to rate the level of handicap of persons in the sample. Validity of the CHART scores was examined by comparing the scores of the persons who were deemed to have high levels of handicap with those who had low levels of handicap (as categorised by the rehabilitation professionals). Whiteneck et al. (1992a) reported that validity of the instrument was supported by the significant differences between the two groups on the measure of handicap. See Appendix 6 for CHART.

Measure of Physical Fitness

Cardiorespiratory fitness levels were assessed by VO_2 max assessment using indirect open circuit spirometry with an arm ergometer. A Sensormedics Vmax 29 Series metabolic cart was utilised. A maximal exercise test was required because the regression equations used to predict VO_2 from a sub-maximal test are not valid for use with

quadriplegic populations due to the sympathetic nervous system changes (Hoffman, 1986).

Prior to exercise, the continuous incremental exercise testing protocol was explained fully to the participant. They were instructed to exercise until they felt they were unable to continue. However, they were also assured that if they felt that they had to stop exercising they could stop at any time. Any questions the participants had regarding the protocol were answered at this time. The participant was then familiarised with the Monarch arm ergometer and the height of the table was adjusted so that the participants shoulders were in line with the axis of the arm crank. A short individual warm up was done before the subject was prepared for the exercise testing protocol. Adaptive cuffs were available for use in the event that the participant did not have sufficient hand function to maintain contact with the arm ergometer handles. Preparation for the exercise protocol included placement of a polar electro heart rate monitor around the participant's chest. Heart rate was then picked up by the remote monitor on the metabolic cart. Subsequently, a mask was secured over the participant's mouth and nose. The mask was used to collect expired gases for analysis in the metabolic cart. Seal of the mask was ensured prior to the beginning of testing and volume of expired air was closely monitored throughout the testing for any changes that may have indicated loss of seal of the mask. In addition, prior to data collection calibration of the metabolic cart with reference gases was performed.

Once the participant was completely prepared and the metabolic cart calibrated, resting baseline values for heart rate, oxygen consumption, respiratory quotient and volume of expired air were determined over a five minute period. Following baseline data collection the exercise portion of the protocol commenced. The VO_2 max protocol used followed the guidelines as outlined by Van Loan et al. (1987). However, because of the limitations of our equipment, primarily the difficulty in achieving small enough workload grades for the quadriplegic participants, the protocol was modified so that workload increases could be more gradual. This was accomplished by initially only increasing the rate at which the subjects were working as opposed to the resistance on the flywheel. Without this modification many of the quadriplegic individuals would not have been able to complete enough incremental stages to reach peak VO_2 .

For all the participants, each incremental stage was two minutes long. For the quadriplegic subjects, the exercise protocol started with no resistance on the flywheel at a rate of 60 revolutions per minute (rpm). A metronome was used to assist the participant to maintain the appropriate cadence. Progressions initially occurred only by increasing the number of revolutions per minute performed (resistance on flywheel remained at zero) with an increase of 10 each stage, up to a maximum of 80 rpm. Once 80 rpm were achieved, the rate was held constant and workload progressions of 112 kpm were made at each subsequent stage.

The protocol for the paraplegic participants was similar, however, after starting at 60 rpm with no resistance on the flywheel, they were progressed more rapidly with rpm and workload increasing simultaneously for the first two stage progressions. Once a rate of 80 revolutions per minute was reached, subsequent increases in workload were accomplished solely by increasing the resistance on the flywheel. Workload increments at each stage were 112 kpm for the paraplegic participants. Throughout the arm cranking all participants were verbally encouraged to maintain the appropriate rate. The test was stopped when the subject was no longer able to maintain the rpm at the set rate (Hooker et al., 1993). Attainment of VO_2 peak was confirmed when a plateau in oxygen consumption was reached in spite of the work load being increased past the work intensity that first resulted in the maximum values (Thoden et al., 1982). Other criteria used to ensure that VO_2 peak was reached included the subject's report of exhaustion and a ratio of carbon dioxide produced and oxygen consumed (R value) in excess of 1.00 (Thoden et al., 1982). Peak VO_2 was represented by the highest value recorded during the test, averaged over 20 seconds (Dallmeijer et al., 1997). Three subjects were unable to use the arm ergometer either due to elbow or shoulder range of motion contractures. For those persons, an incremental aerobic work out was completed with free weights. However, because of the difference in protocols, fitness measures for those three subjects were excluded from the analysis.

Throughout testing the subjects were monitored for: 1) onset of angina or angina like symptoms; 2) signs of poor perfusion such as light-headedness, confusion, pallor, cyanosis, nausea or cold and clammy skin; 3) noticeable or unexpected changes in heart rate in relation to level of spinal cord injury; and 4) physical and verbal manifestations of

severe fatigue (American College of Sports Medicine, 1995). In the present study, no subjects experienced any of these symptoms; thus no tests had to be terminated by the researchers.

Measure of Leisure Time Physical Activity

In the current study, present physical activity status was determined using the leisure time exercise questionnaire (Godin & Shephard, 1985) (Appendix 7). It is a short (four question) assessment of physical activity and was devised to allow classification of people into activity categories in order to examine physical activity behaviours and their relationships to psychosocial variables (Godin & Shephard, 1985). This instrument has been used previously to assess physical activity in a group of persons with spinal cord injury (Noreau et al., 1993). The relationship that demonstrated the strongest correlation (concurrent validity) was between maximal aerobic power (VO_2 max) and reported strenuous exercise ($r=0.35$) (Godin & Shephard, 1985).

The physical activity questionnaire was administered at the testing site and participants were assisted as necessary with interpretation of the questionnaire.

Quantitative Data Analysis

Statistical analysis was performed using SPSS for Windows Advanced Statistics program, Version 7.5. Before any statistical analyses were completed, the data was examined for the presence of outliers, normality, homoscedasticity and linearity (Tabachnick & Fidell, 1989).

Descriptive statistics were reported for each of three groups: high quadriplegics (C5 and C6), low quadriplegics (C7 and C8) and paraplegics. The descriptive statistics included means and standard deviations for age, duration of injury, objective quality of life (OQOL), subjective quality of life (SQOL), fitness (MVO_2), physical activity (PA) and body mass index (BMI). A one way ANOVA was used to determine whether there were differences in the dependent variables among the three level of injury groupings.

Correlational data analysis was conducted to examine the relationships between fitness, physical activity, objective and subjective quality of life in each of the three subgroups: high quadriplegia, low quadriplegia and paraplegia. In addition, the relationships between age and duration of injury and the four primary variables of interest were examined. Pearson product moment correlation and Spearman rank order correlation were used to examine the relationships. Spearman rank order correlation was used when the data deviated substantially from normalcy (Diekhoff, 1992). In this investigation the data for the measure of objective quality of life were positively skewed and thus Spearman rank order correlation was used to examine the relationships with the objective quality of life variable. Spearman rank order testing was used only for the relationships that involved the objective quality of life scores.

Finally, a one way ANOVA was performed to determine if there were significant differences between the high fit and low fit groups and the high and low active groups for the demographic (age, duration of injury) and activity variables (MVO₂ and PA) and for the subjective and objective quality of life scores. All results were considered significant at $p < 0.05$.

2.2.3 Results

2.2.3.1 Quantitative Results

The average age of the participants was 35.9 years with a mean duration of spinal cord injury of 14.4 years. Seventy five percent of the individuals in this investigation were male, which closely approximates the gender distribution in the province of Saskatchewan. Forty eight percent of all participants had cervical spinal cord injuries. Thus, persons with quadriplegia were slightly over represented in this investigation as the level of injury distribution in Saskatchewan is typically forty percent quadriplegia and sixty percent paraplegia (North Saskatchewan Branch of the Canadian Paraplegic Association, personal communication, August, 1997). The group of persons with high quadriplegia was comprised entirely of males, the low quadriplegic group consisted of six males and three females and seven females and fourteen males made up the group of persons with paraplegia. All but two of the participants had spinal cord injuries that were

motor complete below the level of the lesion. The two individuals who had sparing of motor function below the level of the lesion both had a paraplegic injury and both used a wheelchair as their primary mode of locomotion. Of the forty participants, nineteen were employed, five were classified as students and sixteen were unemployed. Employment statistics for Saskatchewan were not available, however, in comparison with American statistics our sample had higher employment levels, 47.5% as compared to approximately 30% (Lanig et al., 1996).

Descriptive statistics for the demographic, quality of life and activity variables are presented in Table 2.2.1 for the three subgroups (high quadriplegia, low quadriplegia and paraplegia). There were no statistically significant differences among any of the groups for age or duration of injury. Scores for objective quality of life were lower for both groups of quadriplegic individuals as compared to the paraplegic group; however these differences were not significant. There were no significant differences between the three groups with regard to subjective quality of life. As expected, mean peak VO_2 and physical activity increased progressively as level of impairment decreased, and the group of persons with paraplegia had significantly higher mean peak VO_2 scores than the other two groups. The physical activity scores were significantly different between the group of persons with high quadriplegia and the group of persons with paraplegia; however there were no other significant differences between the groups in relation to the physical activity variable. Body mass index was not significantly different between the three level of injury groupings.

Initial correlational analysis determined that age and duration of injury were not correlated with any of the physical activity or quality of life measures in any of the groups. Additionally, the measures of fitness and physical activity were significantly correlated for the entire group ($r=0.553$, $p<.001$). Correlational analyses were then conducted between the four main variables of interest; the correlation coefficients are shown in Table 2.2.2. Physical activity was significantly correlated with objective quality of life in the group of persons with high quadriplegia and in the persons with paraplegic injuries. The fitness measure was not significantly correlated with the

Table 2.2.1

Age, Duration of Injury, Physical Characteristics and Quality of Life Scores for Level of Injury Groupings.

	High Quadriplegics (C5 & C6) n=10	Low Quadriplegics (C7 & C8) n=9	Paraplegics (T10) N=21
Age (years)	32.4 (6.2)	35.3 (8.8)	37.7 (10.5)
Duration of Injury (years)	13.4 (6.4)	12 (9.3)	15.8 (7.4)
Maximum VO₂ (ml/kg/min)	8.8 (1.5)	8.3 (2.9)	18.4 (6.9)
Physical Activity (arbitrary units)‡	30.5 (22.2)	41.9 (20.5)	55.5 (30.8)
Body Mass Index	22.4 (6.1)	25.9 (7.6)	24.9 (5.0)
OQOL*	420.2 (67.2)	412.3 (55.1)	449.7 (58.2)
SQOL**	27.2 (19.7)	13.8 (13.1)	24.9 (21.2)

Mean (SD)

‡Physical Activity, higher scores indicate greater activity levels

*Objective Quality of Life (OQOL)

Maximum score 500, higher numbers indicate better objective quality of life

**Subjective Quality of Life (SQOL)

Maximum score 90, higher numbers indicate better subjective quality of life

Table 2.2.2

Correlation Coefficients for the Relationships between Fitness, Physical Activity and Subjective and Objective Quality of Life.

	Physical Activity	Fitness
High Quadriplegics n=10		
Subjective QOL	-0.104	-0.26
Objective QOL	**0.841	0.288
Low Quadriplegics n=9		
Subjective QOL	-0.355	0.093
Objective QOL	-0.35	0.159
Paraplegics n=21		
Subjective QOL	0.362	0.005
Objective QOL	*0.462	0.231

Significance Levels

*p<.05

**p<.01

objective quality of life scores in any of the groups. Subjective quality of life was not correlated with the physical activity or fitness measures in any of the groups. Scatter diagrams depicting selected relationships between the variables of objective and subjective quality of life and physical activity for the groups of persons with high and low quadriplegia are included in Figures 2.2.2, 2.2.3 and 2.2.4. In addition, the subjective quality of life scores were not correlated with objective quality of life scores in any of the level of injury groupings.

Further correlational analysis showed that physical activity was correlated specifically with the objective quality of life domains of mobility and occupation in the group of persons with high quadriplegia. See Table 2.2.3. Also, see Figure 2.2.5 for scatter diagram of the occupation domain vs. physical activity for the group of individuals with high quadriplegia. In the group of persons with low quadriplegic injuries, there was a significant negative correlation between the score on the social integration domain and the fitness scores. See Figure 2.2.6 for a scatter diagram of this relationship. In addition, fitness scores were significantly correlated with the physical independence domain in the group of persons with paraplegia.

In examining the groups that were categorised by fitness and activity levels, more fit and active persons were found to have higher scores on the measure of objective quality of life although the differences were not statistically significant ($p=.132$ and $p=.065$ respectively for the fit and active groups). On the measure of subjective quality of life, the groups did not differ. In addition, as shown in Table 2.2.4, more active participants were younger and had shorter duration of injuries, though only the difference in age was significant (duration of injury, $p=.092$).

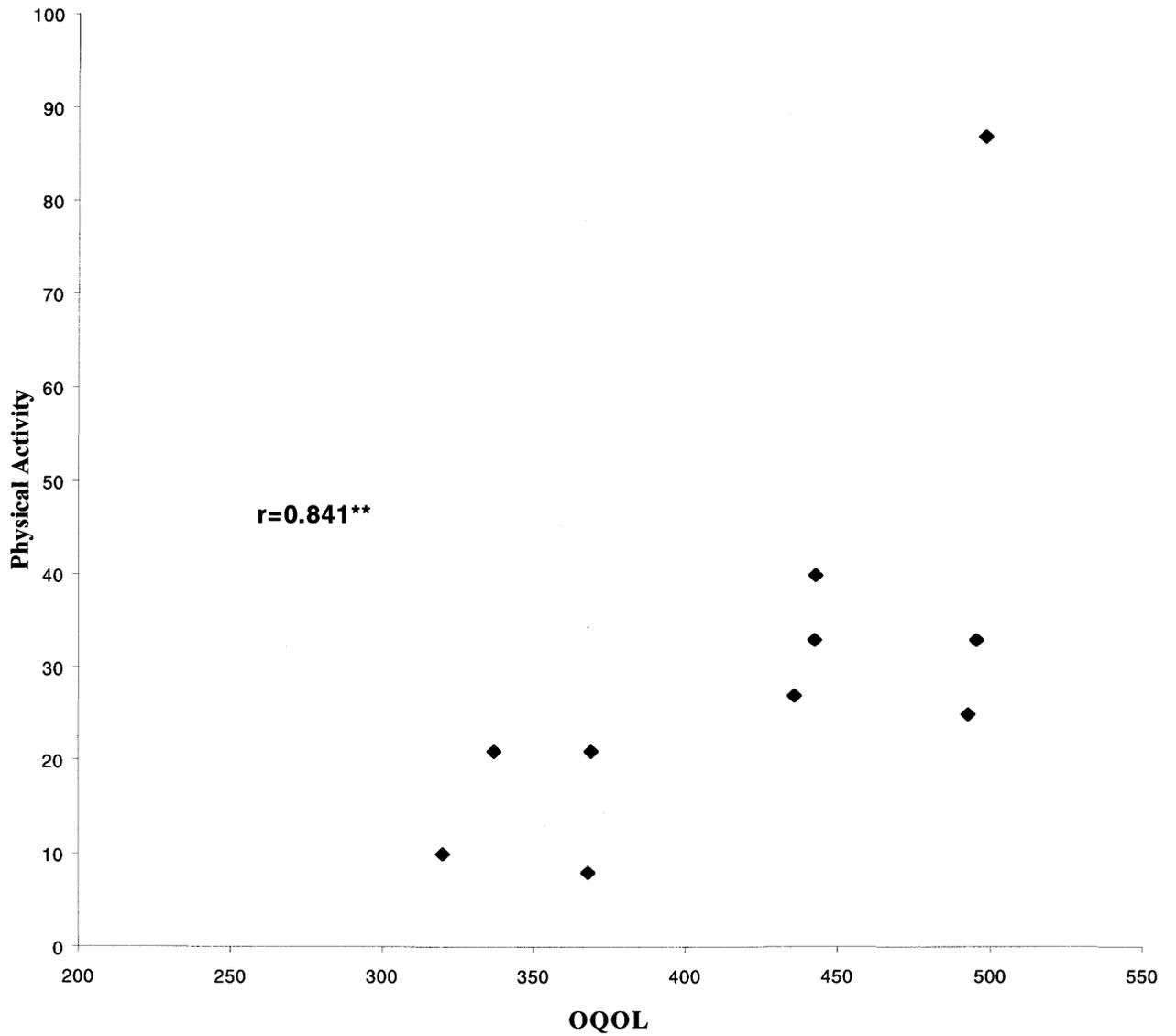


Figure 2.2.2

Scatter Diagram of Physical Activity vs. Objective Quality of Life (OQOL) for Individuals with High Quadriplegia (n=10).

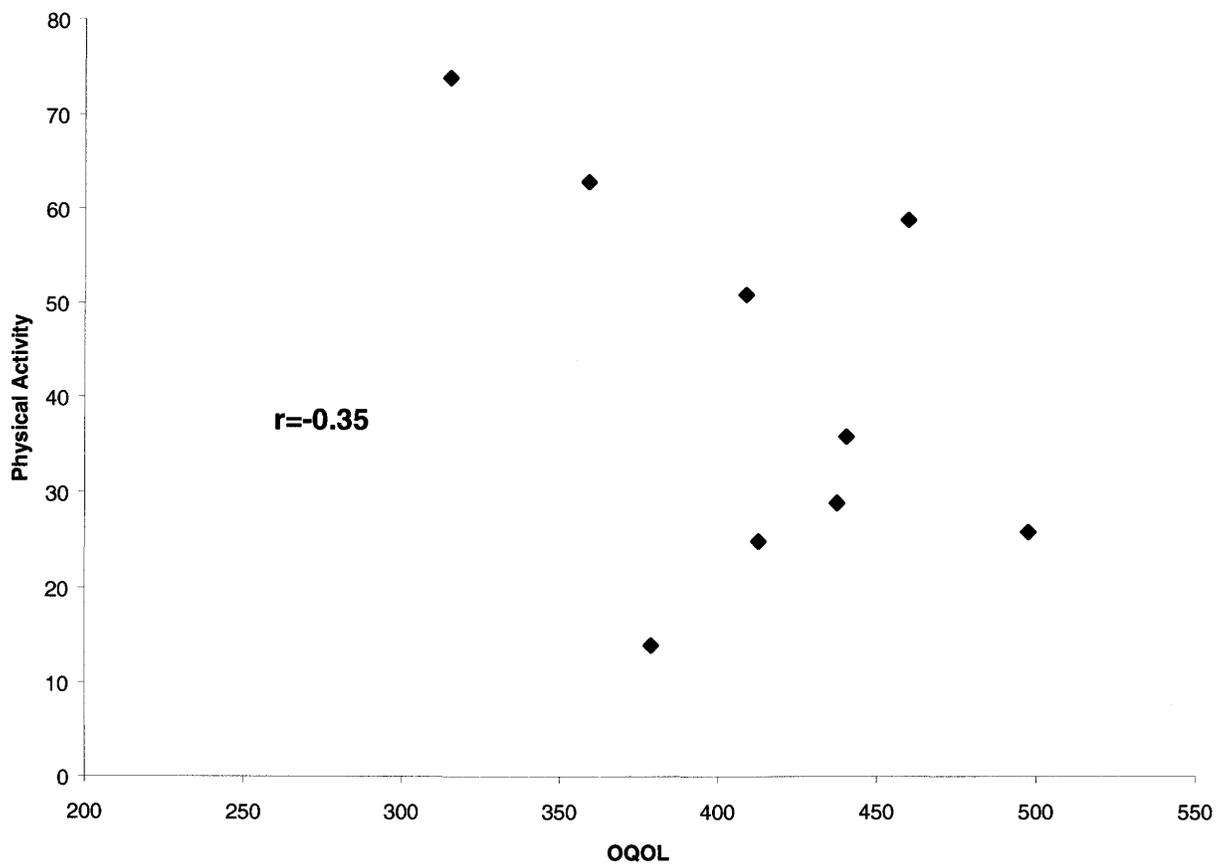


Figure 2.2.3

Scatter Diagram of Physical Activity vs. Objective Quality of Life (OQOL) for Individuals with Low Quadriplegia (n=9).

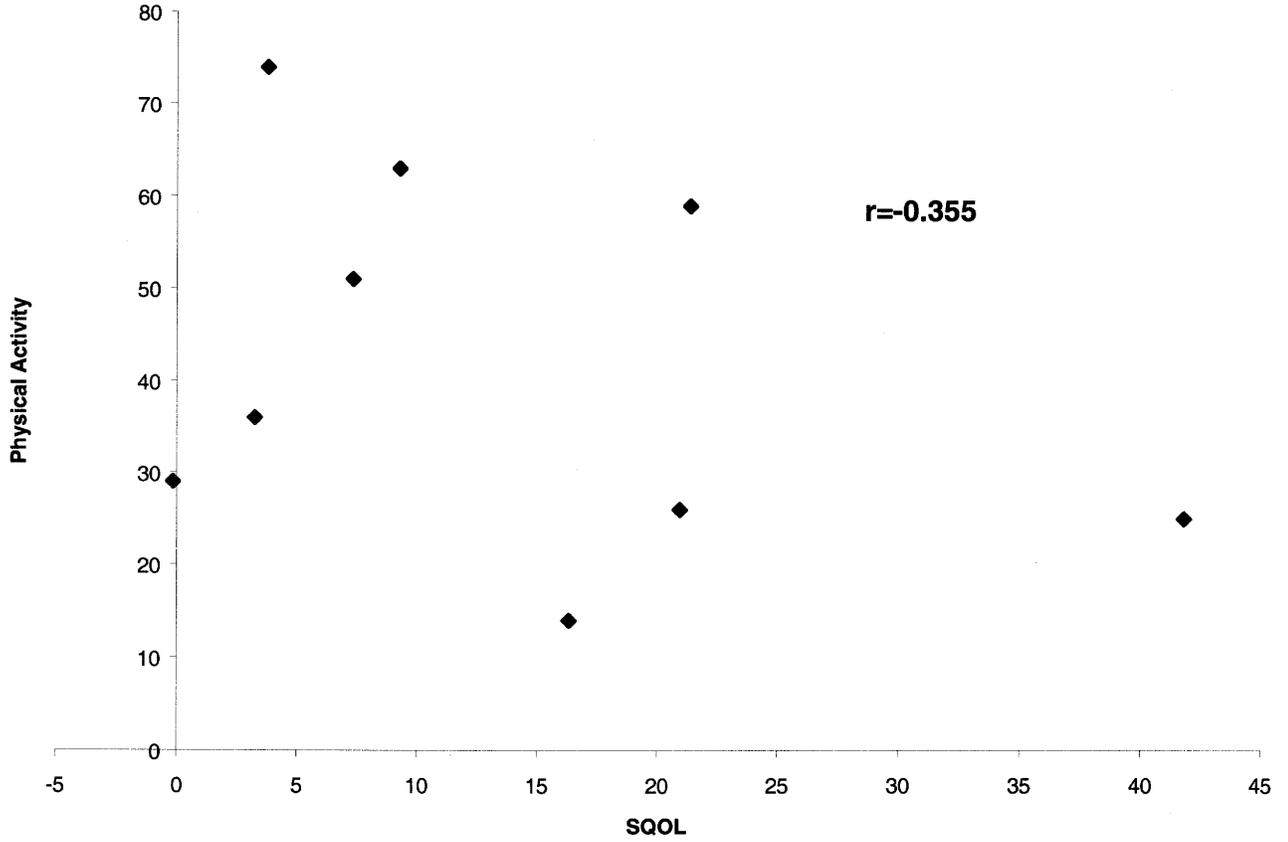


Figure 2.2.4

Scatter Diagram of Physical Activity vs. Subjective Quality of Life (SQOL) for Individuals with Low Quadriplegia (n=9).

Table 2.2.3

Correlation Coefficients for the Relationships Between Physical Activity, Fitness and the Five Domains of Objective Quality of Life.

	Physical Independence	Mobility	Occupation	Social Integration	Economic Self Sufficiency
High Quads					
Physical Activity	0.518	*0.754	**0.932	0.525	0.448
Fitness	0.234	0.129	0.28		-0.149
Low Quads					
Physical Activity	0.317	-0.091	-0.559	-0.538	-0.206
Fitness	0.485	0.321	0.06	*-0.670	0.457
Paraplegics					
Physical Activity	0.388	0.176	0.357	0.267	0.445
Fitness	*0.475	0.329	0.055	0.107	0.124

Significance Levels

*p<.05

**p<.01

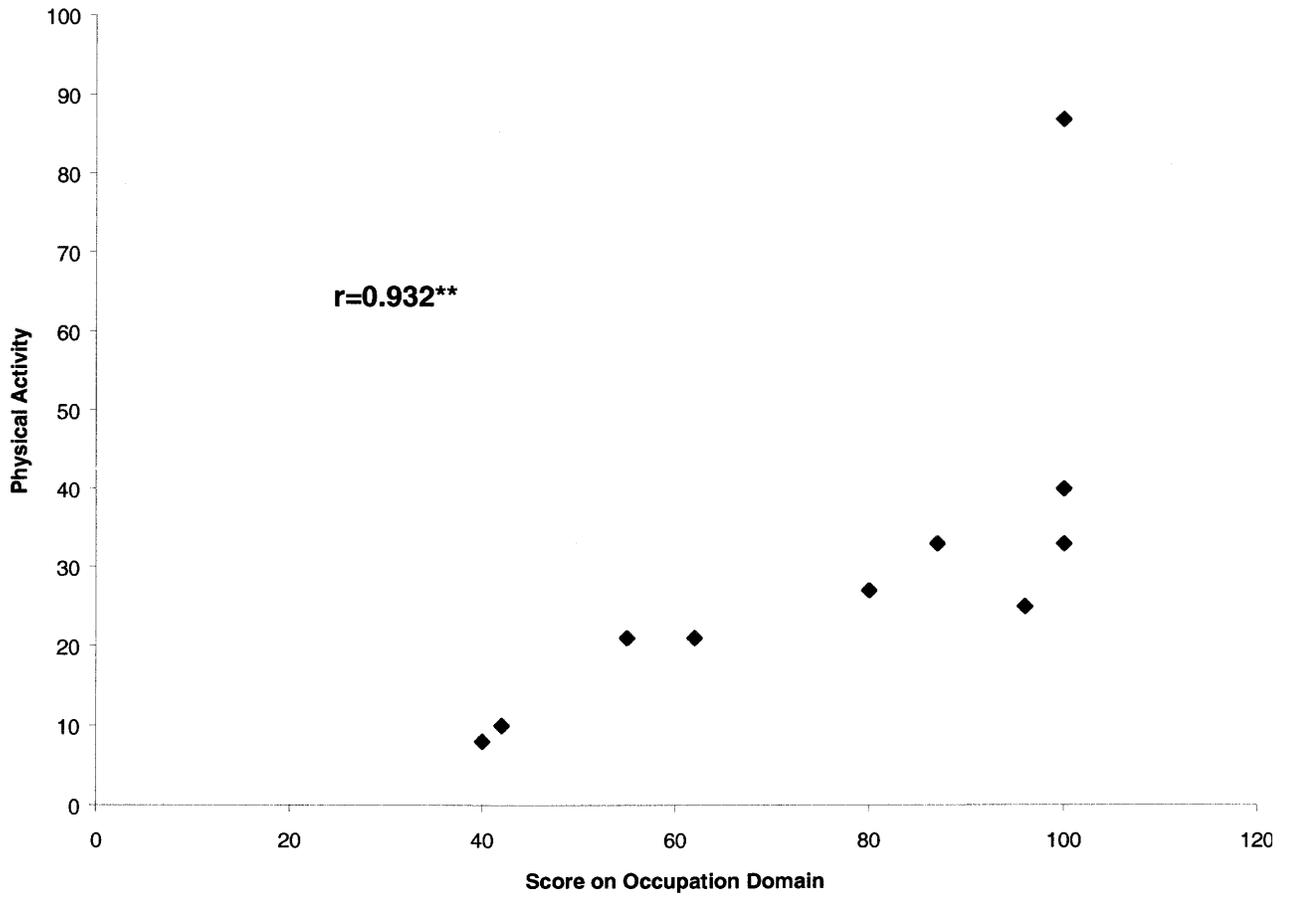


Figure 2.2.5

Scatter Diagram of Physical Activity vs. Occupation Domain of Objective Quality of Life (OQOL) for Individuals with High Quadriplegia (n=10).

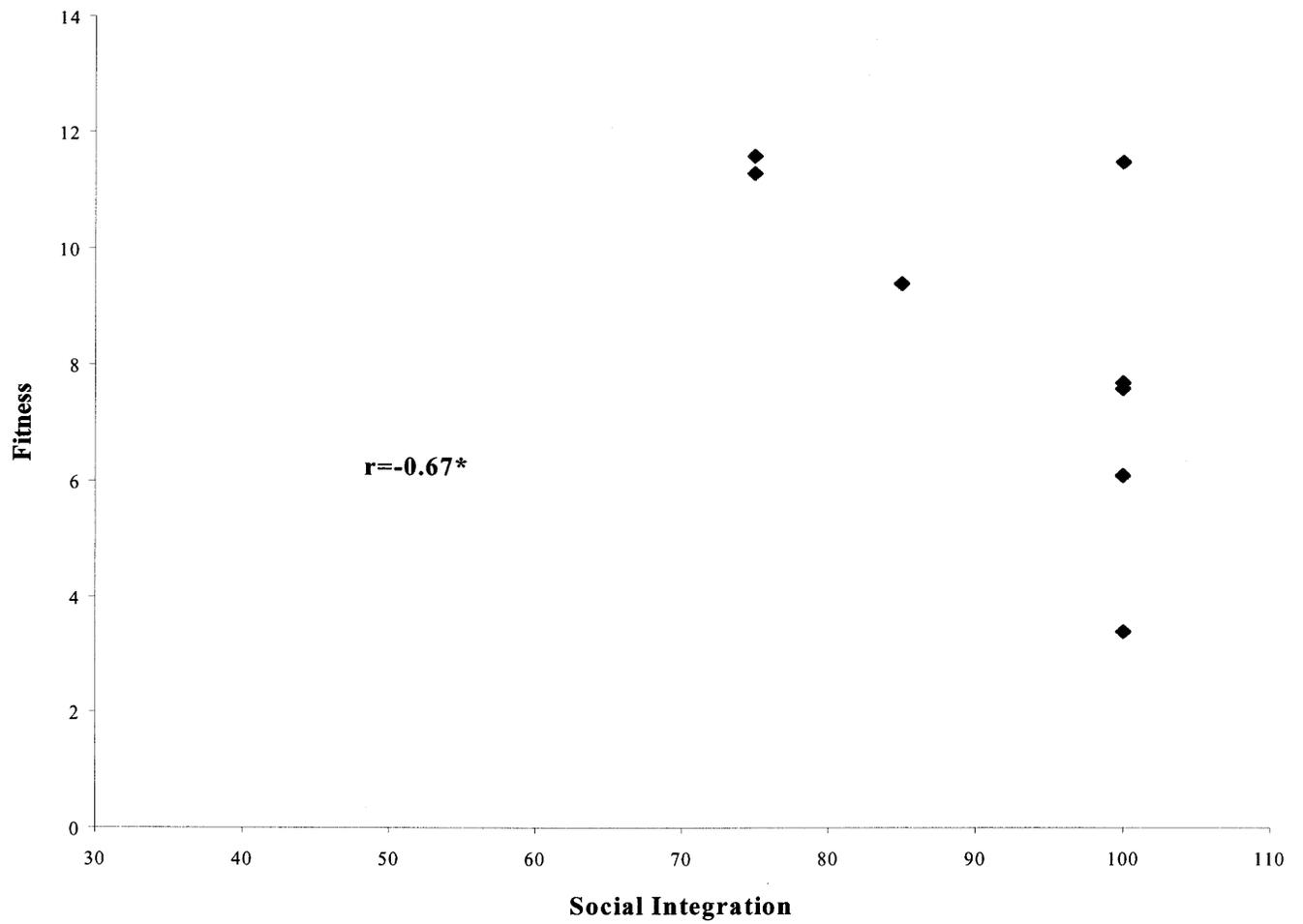


Figure 2.2.6

Scatter Diagram of Fitness vs. Social Integration Domain of Objective Quality of Life (OQOL) for Individuals with Low Quadriplegia (n=9).

Table 2.2.4

Age, Duration of Injury and Quality of Life According to Fitness and Physical Activity Categories.

	High Fitness n=19	Low Fitness N=21	High PA N=21	Low PA N=19
Age (years)	34.1 (6.2)	37.4 (11.3)	31.1 (7.3)	41.1 (8.6)
Duration of Injury(years)	13.3 (6.9)	15.3 (8.2)	12.4 (7.4)	16.5 (7.4)
OQOL*	448 (52.5)	418.1 (66)	450.3 (50.9)	413.9 (66.3)
SQOL **	24.5 (19.7)	21.5 (19.7)	23 (19.7)	22.8 (19.8)

Mean (SD)

*Objective Quality of Life (OQOL)

Maximum score 500, higher numbers indicate better objective quality of life

**Subjective Quality of Life (SQOL)

Maximum score 90, higher numbers indicate better subjective quality of life

2.2.3.2 Qualitative Results

The objective of the qualitative portion of this second study was to increase our understanding of physical activity for persons with spinal cord injury and the role it plays in the quality of their lives. This qualitative information was utilised to supplement the quantitative findings about physical activity and quality of life.

By design, the definition of physical activity was left up to the interpretation of the participants and therefore, there were a variety of ways that physical activity was operationalized. Some persons talked about activity as it referred to the things that they were presently doing in physical therapy, others referred to the activities that they were doing around the house like gardening and housework. Recreational pursuits like fishing and hunting were also categorised as physical activity as was activity that was directly equated with exercise and sports. Physical activity for some of the participants fell into two or three of the categories. Because the first study in this thesis revealed that what mattered most was a person's individual perception of their situation, as the interviewer it seemed most appropriate just to ask if the activity the person did (whatever it was) impacted on their life. Therefore, the following results section will discuss activity as it was defined by the participants and the impact that that activity had on their quality of life.

Following the process of data analysis mentioned previously for qualitative inquiry, two themes about physical activity emerged from the data. The first theme, and the one that was cited most frequently, was that activity was related to improved well being in three areas: physical, emotional and social. The other theme identified was related to the benefits physical activity had on functional ability and physical independence.

Theme One - Improvements in Well Being

Physical

Many of the participants discussed the role that physical activity played in maintaining or improving their general physical health. One man stated, "my body just

functions better if I get some exercise, and I have less of the annoying type of spasms". Participants reported that activity improved their stamina, increased their range of motion and decreased fatigue. They also felt that activity played an important role in the maintenance of an optimal body weight. All of the participants felt that physical activity was in general good for their health and three people specifically discussed the importance of activity in decreasing their risk of heart disease.

In addition to the physical health benefits, some participants said they exercised, in part, just because of the good feeling they got from physically exerting themselves. One woman described working out on the arm ergometer as "a good hurt". Another participant explained, "I think it's good to just get your heart pumping a little bit".

Emotional

A number of the participants indicated that activity improved their self esteem and their self confidence because they were able to participate in similar activities as their able bodied peers. Thus, for younger participants, it was positive for them to go to the gym and work out. For the older participants it was important to be able to be active around the house and in the yard. In both of these instances, physical activity allowed the individuals to do similar things as their able bodied peers. This opportunity freed them from any perceived stigma and was a positive emotional boost. One woman talked about swimming and why she enjoyed it, "...it's freeing to be in the water because you feel lighter and more manoeuvrable, you know, about the same as anyone else". Another participant felt that because she exercised and placed stresses on her body, she was more confident that she could handle and cope with life's everyday stresses. Others felt that because they were active they benefited with increased confidence when wheeling in the community. Venturing out in the community with more confidence was reported to lead to other benefits such as improved social integration and activity within the community. In general, being active appeared to provide an emotional boost for the participants and may have been related to pride that they felt in doing something that enhanced their health.

Social

Enjoyment and fun were mentioned frequently when persons commented about why they were active. One man said, "I enjoy my strolls in the summer time. Whether I get out in the afternoon or whether I go out at eleven o'clock and just go around the block five or six times, it's just nice to be able to get out". A number of participants talked about being active "just to get out". Because less than half of our participants were employed, being active was not only something that was healthy but it was a way to get out of the house. Two unemployed participants specifically talked about boredom as something that they had to contend with day to day and activity was a way to counteract this boredom by just getting out and doing something. Others intentionally combined activity with socialisation and valued it for that reason. "We go down for coffee to my neighbours - we just walk down there, the farthest one down the road". In addition, the individuals that participated in team sports talked about the activity as not only a time to get some exercise, but also a good place to socialise with friends and peers.

Theme Two - Physical Activity as it Relates to Function

In the present study, the results showed that physical activity appeared to improve functional independence. Because physical activity plays an important role in body fat loss or the maintenance of an optimal weight, it was reported to indirectly improve functional independence through weight management. Many participants talked about the impact that weight gain could have on their functional abilities. Individuals with quadriplegic injuries were particularly cognisant of what increased weight could mean to their ability to perform everyday functional activities. One man talked about losing weight through activity and the positive impact it has had on his quality of life, " I guess just losing the weight makes everything easier, like transferring".

Others talked about the direct impact that improved strength and stamina through physical activity had on function. It was reported to be beneficial for transfers, bed mobility, and increased stamina for wheeling. The participants stated that this increased

endurance for wheeling their chair made them more confident and thus improved their quality of life by allowing them greater access to the community.

2.2.4 Discussion

The objective of this investigation was to determine the relationships amongst the variables of fitness, physical activity and quality of life in individuals with spinal cord injury. Participants in the study included 10 persons with high quadriplegic injuries, nine with low quadriplegic injuries and 21 persons with paraplegic injuries. There was no statistical difference between the three groups in terms of chronological age and duration of injury. The mean scores for each group on the measure of objective quality of life were comparable to norms previously established for CHART for similar level of injury groupings (Whiteneck et al.,1992b). In addition, though the objective quality of life scores for the groups were not significantly different, the findings showed that objective quality of life declined with higher levels of spinal cord injury. Objective quality of life scores for each of the three groups in this investigation were, as expected, lower than normative scores established for non disabled persons (Whiteneck et al., 1992b).

Similar to the objective quality of life scores, subjective quality of life scores were not significantly different between groups. However, the subjective quality of life scores did not decrease as level of impairment increased, as the objective quality of life scores did. The group of persons with low quadriplegic injuries were noted to have lower mean subjective quality of life than the other two groups. This finding may be explained simply by the small number of participants in the group with low quadriplegia. However, another explanation for this result could be that persons with high quadriplegic injuries, because they are not physically able to be completely independent, are likely to have daily contact with other persons for assistance. This social contact as well as the physical assistance may allow those persons to focus their energy more on things that they enjoy doing, which would in turn would afford them greater quality of life. In contrast, persons with low quadriplegic injuries have the physical ability to be completely independent and do strive for self sufficiency, however that autonomy is achieved only with much effort. Persons with a paraplegic injury, on the other hand, also have the ability to be

independent but for them independence is achieved much more easily. In addition, because most persons with low quadriplegic injuries will not have any physical assistance or attendants, they may not have the daily social contact that accompanies assistance. Thus, the increased effort required for activities of daily living as well as the potential lack of social contact, may in part explain the lower subjective quality of life scores for the group of persons with low quadriplegic injuries as compared to the other two groups.

It is well established in the literature that persons with quadriplegia have lower potential for exercise capacity than persons with paraplegia (Figoni, 1993). Therefore, it was not surprising that in this investigation, mean fitness scores were significantly lower for both groups of persons with quadriplegia as compared to the group of individuals with paraplegia. The mean peak $\dot{V}O_2$ values reported for the quadriplegic participants in this investigation were lower than means reported by others (Noreau & Shephard, 1994; Noreau & Shephard, 1995) but comparable to values reported by Dallmeijer et al. (1996) and Gass et al. (1980). The peak $\dot{V}O_2$ values reported for the paraplegic participants in this investigation were similar to values reported in other studies (Noreau & Shephard, 1992b; Noreau & Shephard, 1995). Differences in the fitness values reported may be partially explained by differences in subject characteristics between this investigation and others. Many investigations with spinal cord injured persons have utilised primarily trained individuals as subjects (Noreau & Shephard, 1995). Though there were a small number of wheelchair athletes (4) involved in this investigation, the majority of subjects were only minimally or moderately active. Means for body mass index for all subgroups fell at or close to the range reported as the lowest health risk category (BMI range 20-25) (McArdle et al., 1996). However, this finding may be somewhat misleading as there were both very obese (BMI = 44) and extremely underweight individuals (BMI = 11) who participated in this investigation.

Following correlational analysis of the aforementioned data, the findings from this investigation provide evidence that higher physical activity and fitness levels may be related to quality of life. These observations pertain particularly to the objective component of quality of life as physical activity was found to be significantly correlated with objective quality of life for the groups of persons with high quadriplegia and paraplegia. These relationships were not, however, observed with the group of persons

with low quadriplegia. The heterogeneity of the group of persons with low quadriplegia, which consisted of three women and six men, two of whom lived in long term care facilities and two who played wheelchair athletics at the national level, likely contributed to the unexpected findings with this group. For example, one of the fitter and more active men in the group, aged 40, lived in a long term care facility and reported low objective and subjective quality of life. That person's living arrangements likely had a strong bearing on his quality of life, both objective and subjective. Even though his strength and level of fitness may have allowed him to be more independent, which would automatically have given him higher scores on objective quality of life, his living arrangements to a large extent precluded gains in independence and concomitant gains in objective quality life.

Division of the participants into fitness and activity groupings also demonstrated that persons who were more fit and active had better objective quality of life. Though those differences did not reach significance, the results suggest that higher fit and active persons may have better objective quality of life. Qualitative data in turn corroborated these finding with regard to the relationship between physical activity and objective quality of life especially as it related to the important role that physical activity played in functional ability.

Since the objective component of quality of life, as measured by CHART, has been previously defined as an indicator of level of handicap, these findings suggest that spinal cord injured persons with higher activity and fitness levels are less handicapped by their disability or, in other words, more able to fulfil roles that might be considered "normal" for that individual (World Health Organisation, 1980). Additionally, Dijkers, in 1997, found indicators of handicap to be strongly correlated with life satisfaction. Thus, the relationship between fitness, physical activity and reduction of handicap reported in this investigation, in addition to the possible links that fitness and physical activity may have with life satisfaction via its effect on level of handicap, provide evidence to support the development and encouragement of physical activity programs for persons with spinal cord injury.

It is interesting to note that higher correlations were observed between physical activity and objective quality of life as compared to those observed between the fitness

measure and objective quality of life. This suggests that activity may play a more important role in objective quality of life than fitness, which supports earlier work by Rejeski et al. (1996) who found that changes in health related quality of life with physical activity were often independent of changes in fitness. With the spinal cord injured population, because of the limitations in exercise capacity, it is possible that increases in activity levels could occur to some extent without resultant improvements in fitness levels. This may be especially true for individuals with higher levels of injury (i.e. persons with quadriplegia) as exercise capacity for those persons is limited by the relatively small number of active innervated muscles available for exercise as well as by the disruption of the sympathetic nervous system (Figoni, 1993). Even though there may also be limitations to physical activity with higher levels of injury, those restrictions are not nearly as severe as the physiological limitations imposed on exercise capacity by the spinal cord injury. For these reasons, physical activity may be a more sensitive indicator as it relates to the measure of objective quality of life and that greater sensitivity may in part explain the stronger relationship that physical activity, as opposed to fitness, has with objective quality of life.

On examination of the individual domains of objective quality of life, the findings showed that physical activity was significantly positively correlated with the domain of mobility for persons with high quadriplegic injuries. In addition, fitness was significantly correlated with the physical independence domain for the group of individuals with paraplegia. These results support the findings of earlier investigations which reported that higher physical activity (Washburn & Hedrick, 1997) and fitness status (Hjeltnes & Jansen, 1990; Noreau et al., 1993) were related to better functional status; especially for individuals with quadriplegia. The importance of physical activity and fitness to physical independence and mobility was also confirmed through qualitative inquiry as many of the participants felt that keeping fit and active allowed them to be more independent in their day to day life. Greater independence in day to day activities ultimately may allow individuals to have time and energy for more rewarding activities such as involvement in the community, visiting with friends or occupational and educational activities.

As confirmation of the link between greater independence and vocation, in the

present investigation, physical activity status was also significantly correlated with the objective domain of occupation for the group of persons with high quadriplegia. This positive finding supports Reynolds' (1993) statement that persons who are physically active are also active in vocational and educational activities. The link between occupation and physical activity in the spinal cord injured population is not surprising as employment generally requires some reserve of physical capacity, above the capacity for day to day activities. Since activities of daily living often take a lot of energy for a person with a spinal cord injury, someone who is inactive may not have the reserve required to make employment a feasible undertaking. Findings in the literature have generally supported the relationship between physical activity and vocation (Kofsky & Shephard, 1985 as cited in Noreau & Shephard, 1995; Noreau & Shephard, 1992a; Noreau & Shephard, 1992b). One investigation, however, reported no relationship between time spent in sports participation and employment status (Curtis et al., 1986). In that study, though, the group of wheelchair athletes did participate in more hours, though not significantly more hours, of vocational and educational activities per week than the non athletes.

The relationship between fitness and the social aspects of objective quality of life in spinal cord injured persons has not been adequately explored in the literature. It has been assumed that a relationship may exist because of findings with other populations that suggest a beneficial effect of sports and activity (Shephard, 1991). However, the quantitative findings from the present investigation showed that the social integration domain of objective quality of life was not related to the activity parameters, except in the persons with low quadriplegic injuries, who demonstrated a negative correlation between the two constructs. This finding with the group of persons with low quadriplegia is difficult to interpret. When the three women were removed from the analysis the correlation became non significant but remained negative ($p=-0.586$ for fitness; $p=-0.278$ for physical activity). Subsequently, the two persons who lived in a long term care facility were removed from the analysis and again the correlations remained negative and actually became stronger. It is possible that this finding may be explained in the same way as the lower overall subjective quality of life scores discussed earlier for the group of persons with low quadriplegia. However, these perplexing findings may simply

be related to low power because of the low sample size and further loss of power when participants are removed from the analysis. Judgement of the findings from the group of persons with low quadriplegic injuries should be suspended until further investigations can be conducted to attempt to replicate or refute the present findings.

When the qualitative data was examined with regard to relationship between social integration and the activity parameters, however, the findings indicated that participation in sports and exercise was important to the participant's life, in part, because of the social benefits, such as friendships and the development of social support networks. The discrepancy in the quantitative and qualitative findings in this investigation may be related to the difficulty in determining whether social benefits associated with sport and activity are different and separate from social benefits that may be realised through other forms of goal oriented activity (Shephard, 1991). It is possible that social benefits of sport and physical activity are primarily an individual finding and are most evident and best understood through qualitative inquiry processes.

Although the present study has shown a significant relationship between fitness and physical activity and objective quality of life, no relationship was observed between subjective quality of life and the activity parameters in any of the subgroups. The findings from qualitative inquiry, however, did indicate a relationship between activity parameters and subjective quality of life. The first theme reported in the qualitative results eluded to the benefits that activity had on emotional, social and physical well being. In addition, physical activity was reported to improve physical independence and was viewed as important to overall subjective quality of life because of its' benefits to one's health and independence and its' role in generally maximising an individual's potential. It is possible that an increased sample size in the quantitative portion of this study may have confirmed the qualitative findings with regard to the relationship between physical activity and subjective quality of life. However, it is also possible that a person's overall perception of their quality of life and the relationship that perception may have with activity is confounded by other domains of quality of life; areas not generally impacted by physical activity. For example, a person who is fit may be satisfied with their health and function. However, if satisfaction with finances or marital status is low then that person's subjective quality of life score would be lower thus

reporting little relationship between the constructs of subjective quality of life and fitness. Because subjective quality of life is a broad, complex representation of all aspects important to a person's life, however, all components must be taken into account when reporting the construct. In fact, in hindsight, it may have been unreasonable to expect a relationship to be found between an intervention like fitness and activity and the broad construct of subjective quality of life. If a health related quality of life measure had been available and utilised in this investigation, it is more likely that a relationship between subjective aspects of quality of life and fitness and activity would have been found as potential confounding factors like finances and occupational status would not have been included in the representation of health related quality of life. In essence, a health related quality of life measure may have been more sensitive to changes in fitness and physical activity and thus more likely to demonstrate a relationship between the constructs. In the present investigation, though, in which a global subjective quality of life measure was used, there was no relationship found between subjective quality of life and the activity parameters.

The lack of a relationship found between subjective and objective indicators of quality of life in this investigation was contrary to the findings of Fuhrer et al. (1992) who reported that life satisfaction, as measured by LSIA-A, was positively associated with the social integration, occupation and mobility dimensions of objective quality of life, as measured by CHART. However, it should be noted that a subsequent regression analysis in the Fuhrer investigation found that level of handicap did not appear to directly influence subjective life satisfaction as it did not account for a significant amount of variance once self assessed health, perceived control and social support were entered into the equation. The different tools used to measure subjective quality of life may account for the discrepant correlational findings between the present investigation and others (Dijkers, 1997; Fuhrer et al., 1992). The subjective measure of quality of life that was utilised in this investigation is a measure that was specifically designed for individuals with a physical disability, in contrast to some of the measures cited in the meta analysis by Dijkers, such as LSIA-A and the Quality of Life index. Use of condition specific common measurement tools for subjective quality of life will be important in future investigations if relationships with subjective quality of life are to become more clearly

defined.

The lack of a relationship found between subjective and objective indicators of quality of life in the present study may also be explained in relation to adjustment to spinal cord injury. It is possible that as people adjust to their injuries, they perceive lower levels of objective quality of life as satisfactory, thus making objective findings and perceptions of those objective findings incongruous. Montgomery et al. (1996) suggested that persons with spinal cord injury de-emphasise the importance of some components of quality of life, such as mobility and health, and in so doing perceive their quality of life to be similar to persons without disability. Perhaps this is the key to successful adjustment and good quality of life following spinal cord injury; the ability to de-emphasise areas that persons have difficulties with while maximising their potential with the abilities that they do have (Heath & Fentem, 1997).

This investigation also had the opportunity to explore the relationships between age, duration of injury and quality of life. Contrary to other investigations (Krause, 1998; Mehnert et al., 1990; Post et al., 1998; Schulz & Decker, 1985), the present investigation found no relationship between increasing age and decreasing quality of life, either objective or subjective. In addition, duration of injury was not related to subjective or objective quality of life. These findings provide some assurance that, in the present investigation, age and duration of injury were not confounding the relationships between fitness, physical activity and quality of life. However, since this investigation was cross sectional in nature with a relatively small sample size, these findings are not necessarily generalizable to other samples.

The findings from this investigation support the use of fitness and physical activity interventions as effective health promotion strategies for persons with a spinal cord injury. Participants in this investigation who were fitter and more active were generally less handicapped than their inactive peers. Higher levels of handicap (as measured by CHART) have been found to be a significant predictor of depression and psychological distress in persons with spinal cord injury (Tate et al., 1994), indicating that the findings from this investigation may have broader implications. For example, it is possible that physical activity may play a role in improving emotional function, however, that effect may be mediated through the impact of physical activity in the

reduction of level of handicap. Though research in the able bodied literature has suggested a relationship between physical activity and the emotional function component of quality of life (McAuley & Rudolph, 1995), that relationship requires further investigation in spinal cord injured populations.

In spite of the questions that remain to be answered with regard to the relationship between: 1) subjective and objective quality of life; and 2) physical activity and subjective quality of life, it is important to recognise the contribution of physical activity in decreasing handicap and improving objective quality of life in individuals with spinal cord injury. As researchers continue to sort out the relationships between physical activity and fitness and quality of life for spinal cord injured person, health care professionals should encourage active lifestyles for persons with spinal cord injury with confidence that it will benefit that persons' life.

CHAPTER THREE

GENERAL DISCUSSION

The studies described in this thesis explored areas of research that have not, in the past, been adequately addressed in the literature. These areas included: 1) quality of life and spinal cord injury; and 2) the relationships between quality of life and fitness and physical activity in persons with spinal cord injury. The findings from the two investigations contributed to the literature in these areas but have also illustrated that there remains much to be learned.

The objective of first study was to qualitatively explore the construct of quality of life with spinal cord injured persons since there was limited information in the literature about what determines quality of life for spinal cord injured persons (Dijkers, 1997). It was determined that quality of life for individuals with spinal cord injury was multidimensional and comprised of a number of the same domains that represent quality of life for able bodied persons, such as health, relationships and social function, emotional health and finances. Researchers should be aware, however, that issues related to accessibility, physical independence and stigma may play an important role in quality of life exclusively for spinal cord injured persons. The findings from Study One also reinforced the importance of seeking and understanding the individual's perspectives about their situation in order to more fully comprehend the impact of a spinal cord injury on that person's life. The qualitative process utilised in both studies successfully allowed the individual's perspectives to be heard. In addition, the qualitative findings about quality of life from Study One were important because they assisted in the selection of an appropriate quality of life questionnaire for Study Two.

The relationships among the variables of fitness, physical activity and subjective and objective quality of life in persons with spinal cord injury had not been previously reported in the literature. The results from Study One indicated that subjective perceptions of each person's quality of life were important to determine. Additionally,

objective quality of life, a measurement of handicap, was also of interest because level of handicap is an indication of the consequences of disability and impairment for that person. Thus, the objective of the second investigation, which used both qualitative and quantitative methodologies, was to explore the relationships amongst the variables of objective and subjective quality of life and the measures of fitness and physical activity. The quantitative portion of this investigation did not find a relationship between fitness and activity levels and subjective quality of life in spinal cord injured persons. However, the qualitative portion of the study did find that fitness was important to subjective quality of life for some individuals. For example when asked why he exercised, one individual said (after looking at the interviewer in disbelief), “ Well, I don’t have a choice anymore”. He explained that being in a wheelchair made him feel more vulnerable, to the point that he now had no choice but to exercise if he wanted to function optimally; in the community, in a job, in school and with his friends. Not all participants, of course, were as definite about the role of physical activity and fitness in their life, but the majority agreed that they would benefit if they were more active. The benefits of physical activity to quality of life discussed in the qualitative portion of Study Two were specifically related to improvements in emotional, social and physical well being and the benefit that physical activity had to functional independence. Though the benefits of physical activity to a person’s perception of quality of life seemed fairly straight forward during the qualitative interview process, those relationships were not observed in the quantitative portion of the study. Thus, the qualitative findings were important because they served to signal that further research is required.

Previous cross sectional investigations have provided evidence that fitness and physical activity were related to objective measures of functional independence and occupation (Noreau & Shephard, 1992a; Noreau et al., 1993). The second investigation in this thesis supported those earlier findings and additionally suggested a relationship between overall objective quality of life (level of handicap) and fitness and physical activity. In contrast to the findings about subjective quality of life and fitness and physical activity, the qualitative and the quantitative findings both supported a relationship between objective quality of life and fitness and physical activity. These are important findings as other investigations have determined that indicators of level of

handicap, as opposed to indicators of disability or impairment, are most closely related to life satisfaction in persons with spinal cord injury (Dijkers, 1997). Thus, it may be hypothesised that the positive relationship reported between the activity parameters and level of handicap, may also indicate a possible relationship between activity and life satisfaction. This potential relationship requires further investigation. The cross sectional evidence provided in the second investigation in this thesis provides a stepping stone towards further cross sectional investigations and towards crucial longitudinal investigations and intervention studies that will attempt to document cause-effect relationships between the variables in question.

3.1 Implications for Health Professionals

Health care professionals such as physical and occupational therapists, nurses and doctors most commonly treat persons with spinal cord injury either in the acute and rehabilitation stages of recovery following injury or upon the patient's return to the hospital because of health problems. In the early stages of recovery, health care professionals have the opportunity to address many issues related to adjustment and quality of life following spinal cord injury. Therapists should be aware of the multidimensional nature of quality of life following spinal cord injury, as described in Study One of this thesis, and should plan their treatment sessions so that a number of those issues are addressed throughout the rehabilitation process. Unfortunately, in the past, treatment sessions have usually focussed primarily on activities to reduce disability. Too often, important quality of life issues like reintroduction into the community, occupational issues, dealing with stigma and lifestyle adjustments, such as physical activity and diet, if addressed at all, are attended to all at once in the final one to two weeks on the rehabilitation ward. This may not be the most effective or successful way of dealing with these important issues with persons with spinal cord injury. Treatment interventions dealing with quality of life issues must be included and should begin at the same time as interventions to reduce disability with spinal cord injury. As Whiteneck (1997) suggested, success following spinal cord injury is more than the management of disability and "a comprehensive system of care [is needed] to minimize lifetime

complications and handicaps and maximize quality of life” (p. 184).

In addition, there is a specific need for implementation of better health promotion programs, in the rehabilitation setting, in order to improve health and prevent or reduce the frequency of return visits to the hospital with health problems. These health promotion programs could address and assist the person with spinal cord injury in overcoming some of the barriers to fitness and activity identified in the qualitative portion of Study Two. These include: 1) perceived lack of skill or ability; 2) lack of knowledge and confidence about what types of activities to partake in; 3) concerns about the overall safety of activity; and 4) accessibility. Interventions may include education and familiarization with leisure and health promotion options and opportunities within the community and should take place during the time the individual is in the rehabilitation centre or in the first few months following discharge to the community. It is during that time that newly injured persons begin to formulate a plan about how they will optimally live life with a spinal cord injury and health promotion strategies will be an important part of that plan.

CHAPTER FOUR

CONCLUSIONS AND FUTURE RESEARCH

The first study described in this thesis improved our understanding of issues related to quality of life for the spinal cord injured population and reported nine domains that were important to the quality of life. These domains included: 1) physical function and independence; 2) accessibility; 3) emotional well being; 4) stigma; 5) spontaneity; 6) relationships and social function; 7) occupation; 8) financial stability; and 9) physical well being. The results of the second study supported the first hypothesis in showing that higher levels of physical activity and fitness were related to improved quality of life and decreased level of handicap. However, the second hypothesis was not supported as the measures of objective and subjective quality of life were not related. The findings from these investigations provide a starting place from which future research can continue to build on.

Areas of future research may include the determination of the impact of higher fitness and activity levels on quality of life across the life span of a person with spinal cord injury. Menter et al. (1991) reported that objective quality of life decreases with age. However, it may be hypothesised that higher fitness levels can moderate the detrimental affect of age on objective quality of life. A cross sectional investigation that examines two groups of spinal cord injured persons who differ only on the variables of fitness and previous activity levels may provide some insight about the relationships between fitness, age and objective quality of life. Longitudinal investigations tracking individuals, from spinal cord injury throughout their life, on the parameters of fitness, physical activity and subjective and objective quality of life would, of course, be very valuable in increasing our understanding of the impact of fitness on quality of life over the life span. To my knowledge, there have not been any longitudinal studies to date that have examined the impact of a consistently active lifestyle and higher fitness levels on global quality of life or factors like employment and functional ability. Typically intervention studies with

spinal cord injured persons have recorded changes in dependent variables like max $\dot{V}O_2$ or maximum muscular power with a training program. In the future, longitudinal and intervention studies involving fitness and persons with spinal cord injury would benefit from the inclusion of important outcomes like quality of life and level of handicap in addition to the more traditional fitness parameters.

Another implication of the current findings in this thesis is with regard to the measurement instruments used for this type of research. It will be important, in the future, that quantitative studies examining subjective quality of life use similar, appropriate measurement tools. In the past, the findings in the literature with regard to subjective quality of life have been considerably weakened because of the use of a number of different measurement tools across studies. The use of various tools has made comparison between studies difficult. Utilisation of like measurement tools will be crucial in increasing the knowledge base about subjective quality of life and the relationships it may have with other constructs.

Lastly, future investigations with regard to quality of life and factors that may improve it may benefit from the use of qualitative methodologies. In these investigations, qualitative methodologies were useful not only as the primary methodology in the first study but also as a supplement to the quantitative findings in the second study. In some instances qualitative data provided possible explanations for the quantitative findings. With a construct as individual as quality of life, it was very useful to use an approach that allowed not only the similarities but also the differences between persons to be recognised.

Research with regard to fitness and quality of life with spinal cord injured persons is in its infancy. Much more remains to be learned about this topic from both cross sectional and longitudinal investigations. In addition, with the current interest in ageing with spinal cord injury, future research should seek to find interventions that may assist in maintaining or improving quality of life as a person ages.

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Appendix 1 – Participant Consent Form Study 1

Quality of Life in Spinal Cord Injured Persons: Evaluating Current Status and the Impact of Physical Activity/ Physical Fitness

Participant Consent Form

We would like your assistance in a project to be conducted at the College of Physical Education. The project is under the direct supervision of myself, Dr. Karen Chad from the College of Physical Education at the University of Saskatchewan. Trish Manns, a graduate student currently working on her Master's degree, will be working with you throughout your involvement in the project. She is a physiotherapist and has six years experience working with persons with disabilities at the Rehabilitation Centre at SCH.

The goal for the first part of the study is to develop a questionnaire that is capable of accurately measuring your quality of life. It is important to develop this measure so that we can determine what the health care system can do to help enhance your health and well being. In addition, it will help to define the role that your actions can play in your overall quality of life.

We are looking for 20 people with spinal cord injury, who will agree to be interviewed about the aspects of their life that are affected by spinal cord injury. The interview will take approximately one hour of your time and will be arranged at a time and place that is convenient for you. The interview will be tape recorded. However, you will be free at any time to ask that the tape recorder to be turned off. Also, any time following the interview, your responses can be changed or deleted from the tape if you wish.

Upon completion of the study, if you wish, we will meet with you to discuss your individual results as well as the overall findings of the study. However, you are more than welcome at any time during the study to discuss with us individual data collected to date.

Your participation in this study is completely voluntary. All information that is gathered through this study will be kept completely confidential. When the project is written up, the results will be reported without the use of your name. You have the right to request that any part of the information obtained be deleted from your records. You will also be given the opportunity to confirm any of the information you have given to us before it is used in any written documents. If you wish, you may withdraw from the study at any time.

If you would like to be a part of this project, please complete the attached form to indicate your consent. If you have any questions or concerns about this study, please contact myself, **Dr. Karen Chad (966-6511)** or **Trish Manns ()**.

I have read and understand the purpose of this study and my involvement in the project. I am aware that I will remain anonymous throughout the study and in any written results of the data collected through participation in this project. I am aware that I have the right to withdraw from the study at any time. I acknowledge that I have received a copy of the consent letter for my records.

Participant's signature: _____ **Date:** _____

Researcher's signature: _____ **Date:** _____

Witness' signature: _____ **Date:** _____

Appendix 2- Semi Structured Interview Guide Study 1

Quality of Life:

What are the things that are affected by a SCI?

How do these things affect how good your life is?

Does the SCI prevent you from complete satisfaction in these areas? Or Are these things important to your QOL and restrict how good your life can be?

Does a SCI have affect how good you life can be? (Either negatively or positively). How (in what ways)?

What do you think QOL means?

What things are important to your life (your QOL)?

How does the SCI affect these things?

Do you think that where you live (urban or rural) makes a difference to how good your life can be (makes a difference to your QOL)?

Are different things more or less important to your life now that you have a SCI? Or Does a SCI change what is important to your life?

Physical Activity and Quality of Life

Tell me about activity and exercise before your injury? Was it an important part of your life?

Do you make a point of being active now? Why - Why not?

Is it important to your life now? Why?

Appendix 3 – Participant Consent Form Study 2

Fitness, Quality of Life and SCI Project Participant Consent Form

This study will investigate the relationships between fitness and quality of life in spinal cord injured persons. Your participation in this project will involve one testing session of approximately two to two and a half hours in length. The testing will take place at the College of Physical Education at the University of Saskatchewan. The following procedures will be done:

1. Completion of a background and medical history questionnaire.
2. Completion of a questionnaire about your present physical activity habits.
3. Completion of one graded exercise test to determine your level of fitness. The exercise test will be done on an arm ergometer (arm bike). Expired air will be collected prior to the exercise for five minutes as well as for the exercise and recovery stage (also 5 minutes). The time of the exercise phase will vary likely between 5-10 minutes. The speed that you pedal will be kept constant. The resistance will begin at a low level and will be gradually increased. It is important that you realize that you may stop whenever you wish because of feelings of fatigue or any other discomfort. You may experience some short term fatigue following the exercise test.
4. Completion of two questionnaires about the things that are important to your quality of life.

Upon completion and analysis of the data gathered in the procedures outlined above, a summary of the results will be sent to you. However, you are more than welcome during the course of the study to ask questions at any time. We will be glad to discuss your results with you when they become available and we welcome your comments and suggestions throughout the course of the study.

Your participation in this study is completely voluntary. All information that is gathered through this study will be kept completely confidential. When the project is written up, the results will be reported without the use of your name. If you wish, you may withdraw from the study at any time.

Participant's Statement:

I, _____, understand the purpose and procedures of this study as I have read, or have had described to me, and I voluntarily agree to participate. I understand the contents of the consent form, the proposed procedures and the possible risks. I am aware that I will remain anonymous throughout the study and in any written results of the data collected through participation in this project. I am aware that I have the right to withdraw from the study at any time.

Participant's signature: _____ Date: _____

Witness's signature: _____ Date: _____

Researcher's signature: _____ Date: _____

Appendix 4 – Background Information Questionnaire

Fitness, Quality of Life and SCI Project
College of Physical Education, University of Saskatchewan

Background Information

Name: _____ Date: _____

Address: _____

Phone Number: _____

Date of Birth: day _____ month _____ year _____

Date of spinal cord injury: day _____ month _____ year _____

What is the highest level of education you have attained?

- _____ Grade 12
- _____ Some Trade, Technical or Vocational School or Business College
- _____ Some University
- _____ Diploma or Certificate from Trade, Technical or Vocational School or Business College
- _____ Bachelor's degree
- _____ Master's degree
- _____ Degree in Medicine, Dentistry, Veterinary Medicine or Optometry
- _____ Ph.D.
- _____ Other

What is your current employment status?

- _____ Employed
- _____ Student
- _____ Other
- _____ Homemaker
- _____ Unemployed
- _____ Unable to work

Are you in the same job now as you were prior to your SCI? ___ Yes ___ No

What is your current marital status?

- _____ Single
- _____ Married/Living common-law
- _____ Separated or divorced
- _____ Widowed

Family Physician _____

Sask Health # - _____

Background Information Questionnaire (con't)

Past Medical History:

Have you ever had or been told by your doctor that you had any of the following conditions (Please check appropriate answer):

Heart disease or angina	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Don't know
Heart attack	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Don't know
High blood pressure	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Don't know
Low blood pressure	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Don't know
High blood cholesterol	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Don't know
Stroke	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Don't know
Tuberculosis	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Don't know
Asthma	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Don't know
Chronic colitis	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Don't know
Diabetes	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Don't know
Thyroid condition	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Don't know
Kidney disease	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Don't know
Hepatitis	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Don't know
Rheumatoid arthritis	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Don't know
Other arthritis	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Don't know
Any fracture	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Don't know
Any cancer	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Don't know
Pressure sores	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Don't know
Urinary tract infection	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Don't know
Spasms	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Don't know

Do you have regular pain (i.e. 2 times a week or more) Yes No
If yes, where is your pain located? (i.e. Back, neck etc)

What medications are you on regularly (if any)? _____

Have you spent a night in the hospital? in the last 1 year Yes No
last 2 years Yes No

Quality of Life Profile: Physical and Sensory Disabilities Version

What is Quality of Life?

Quality of Life, in simple terms, means:

"How good is your life for you?"

The answer to this question is a measure of a person's Quality of Life.

To answer the question "How good is your life for you?" you are asked to focus on yourself and to rate some aspects of your life. These are all rated on a simple scale of 1-5. The aspects of your life are divided evenly into 9 areas -- areas that we think are part of the lives of all people.

The nine areas that are part of the lives of all people are:

1. My body and my health
2. My thoughts and feelings
3. My beliefs and values

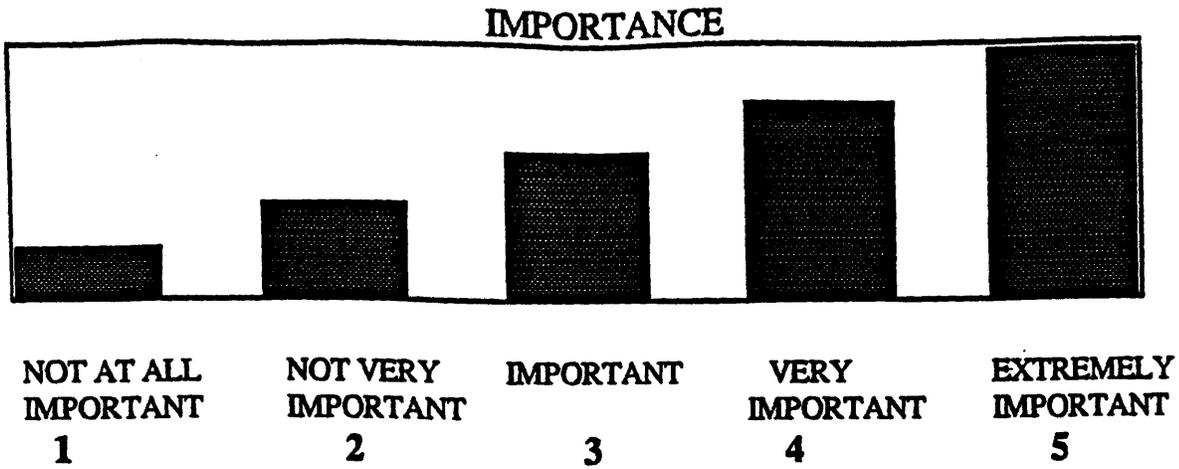
4. Where I live and spend my time
5. The people around me
6. My access to things in my community

7. The practical things I do
8. The things I do for fun and enjoyment
9. The things I do to cope and change

First, you will rate the same aspects two times, using two different questions: How important to me is...? and How satisfied am I with...? Then, you will indicate how much control and possibility for improvement exist in the 9 areas of your life. This sounds like a lot, but you will find that you can rate them rather quickly.

Please give the ratings that best match your views.

Rating scale:



DON'T KNOW: DK

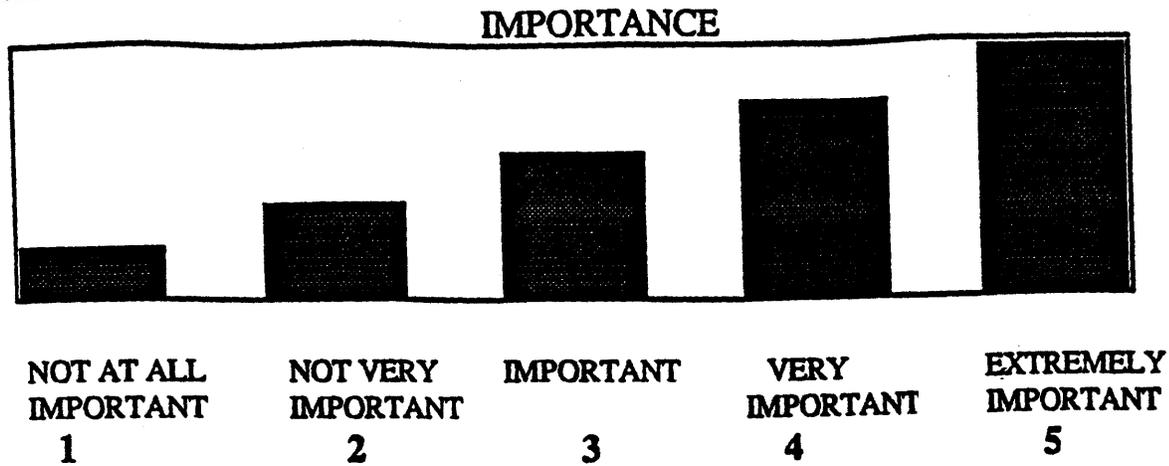
NOT APPLICABLE: NA

My body and my health

How important to me is -- ?

1. Being physically able to get around my home. _____
2. Being physically able to get around my neighbourhood. _____
3. Being physically able to use public transportation. _____
4. Being physically active and keeping fit. _____
5. Getting enough sleep and rest. _____
6. Good nutrition and eating the right foods. _____
7. Having enough energy to do the things I want to. _____
8. Maintaining my personal hygiene and caring for myself, by MYSELF. _____
9. Maintaining my personal hygiene and caring for myself,
WITH THE ASSISTANCE OF OTHERS. _____
10. My personal appearance. _____
11. How I am able to manage the pain that I have. _____
12. My overall physical health. _____

Rating scale:



DON'T KNOW: DK

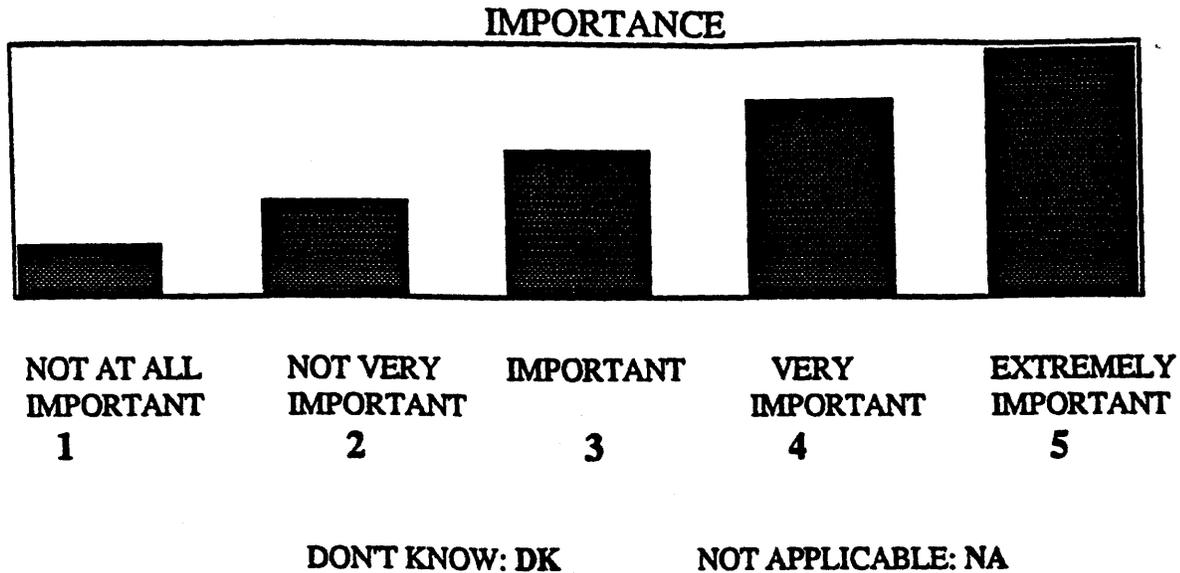
NOT APPLICABLE: NA

My thoughts and feelings

How important to me is -- ?

1. Accepting the way I am. _____
2. Making my own decisions. _____
3. Acting independently, on my own. _____
4. Being able to remember things. _____
5. My level of stress. _____
6. The mood I am usually in. _____
7. Coping with what life brings. _____
8. Feeling good about myself. _____
9. Having a positive attitude towards life. _____
10. Having a sense of humour. _____
11. My mental health. _____

Rating scale:

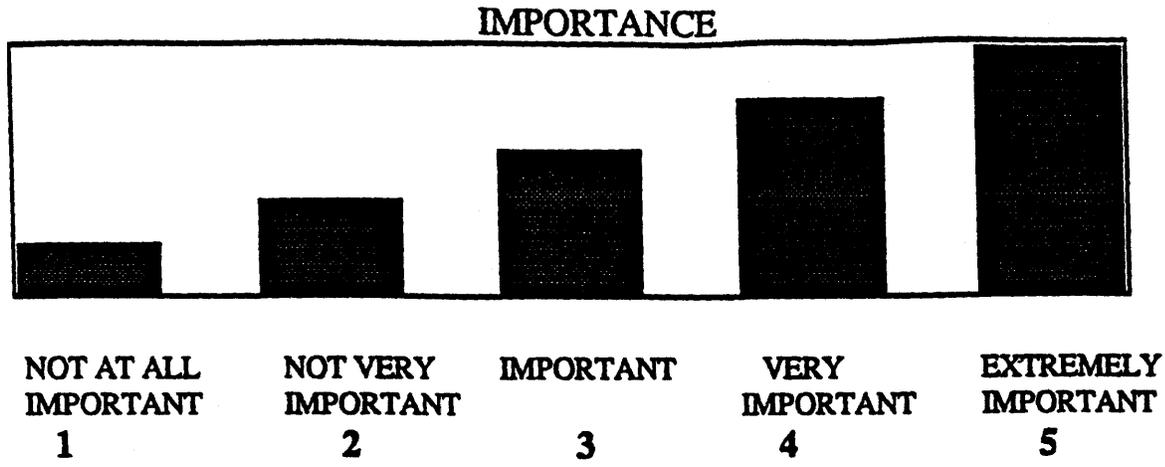


My beliefs, attitudes and values

How important to me is -- ?

1. Being caring towards other people. _____
2. Celebrating birthdays or special events. _____
3. Feeling peaceful within myself. _____
4. Feeling that my life has purpose. _____
5. Sharing love with other people. _____
6. Having my own ideas of right and wrong. _____
7. Having religious or spiritual beliefs. _____
8. Having things to look forward to. _____
9. Participating in religious or spiritual activities. _____

Rating scale:



DONT KNOW: DK

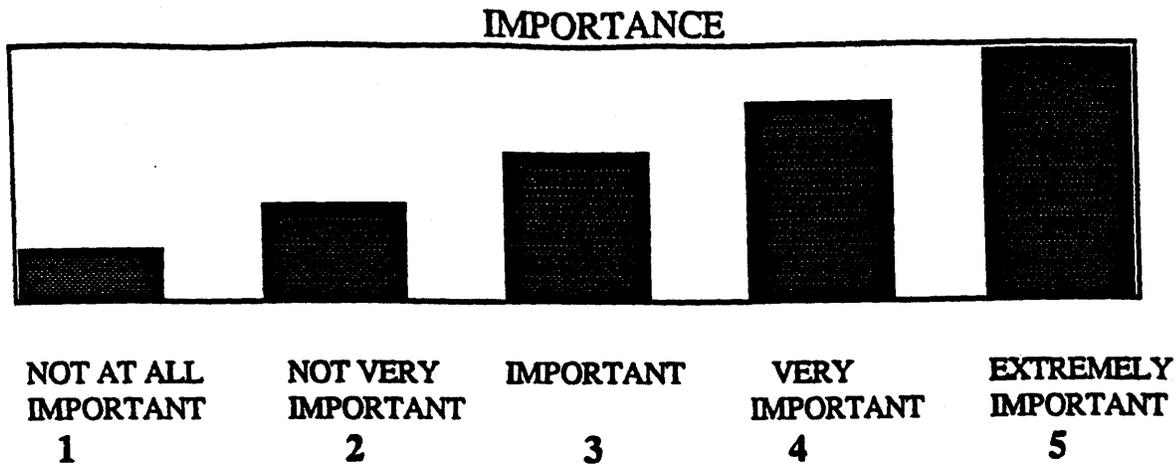
NOT APPLICABLE: NA

Where I live

How important to me is -- ?

- 1. Where I live. _____
- 2. Living in a safe place. _____
- 3. Having a space for privacy. _____
- 4. Having my own personal things. _____
- 5. Living in a comfortable place. _____
- 6. Living in a place with enough space. _____
- 7. Living in a place that is physically accessible to me. _____
- 8. What part of Canada I live in. _____
- 9. Living near my family or friends. _____
- 10. What neighbourhood I live in. _____
- 11. Living in a safe neighbourhood. _____

Rating scale:



DON'T KNOW: DK

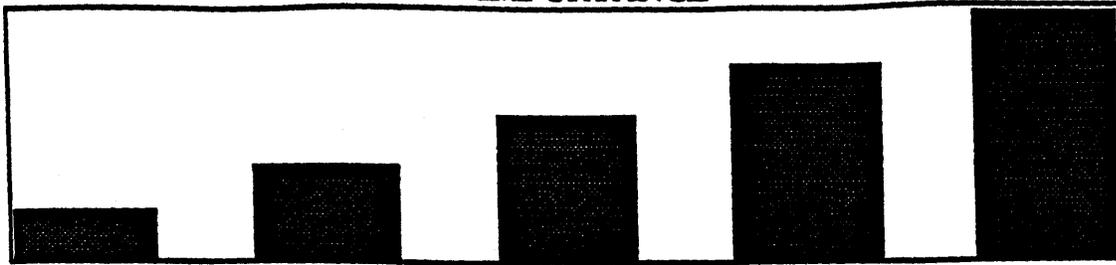
NOT APPLICABLE: NA

The people around me

How important to me is -- ?

1. Having a spouse, partner, or special person. _____
2. Having friends. _____
3. Being close to some members of my family. _____
4. Having acquaintances. _____
5. Having neighbours I can turn to. _____
6. Being able to count on family members for help. _____
7. Having people nearby who I can communicate with. _____
8. Meeting in social/cultural/interest/faith groups. _____
9. The degree to which I depend on people in my family. _____
10. Having social events to attend. _____
11. Being accepted by people I see regularly (at work, school, etc.). _____
12. Sexual intimacy. _____
13. Being respected by people around me. _____

IMPORTANCE



NOT AT ALL
IMPORTANT
1

NOT VERY
IMPORTANT
2

IMPORTANT
3

VERY
IMPORTANT
4

EXTREMELY
IMPORTANT
5

DON'T KNOW: DK

NOT APPLICABLE: NA

My access to resources

How important to me is -- ?

1. Being able to get health services
(from doctors, therapists, nurses, dentists, etc.). _____
2. Being able to get social services (vocational services,
social worker, etc.). _____
3. Being able to get other special services (attendant care, etc.). _____
4. Being able to live in affordable housing. _____
5. Going to places in my neighbourhood (stores, etc.). _____
6. Feeling the government understands my needs. _____
7. Having access to meaningful work. _____
8. Having courses, classes, or programs that I can take. _____
9. Having enough money to live comfortably. _____
0. Having events in my community to go to (movies, concerts, etc.). _____
1. Having programs and services in a language or form I understand. _____
2. Having transportation that allows me to get where I want to be. _____
3. Having adaptive equipment or resources
(wheelchair, braille formats, telephone adaptations, etc.). _____

IMPORTANCE



NOT AT ALL
IMPORTANT
1

NOT VERY
IMPORTANT
2

IMPORTANT
3

VERY
IMPORTANT
4

EXTREMELY
IMPORTANT
5

DONT KNOW: DK

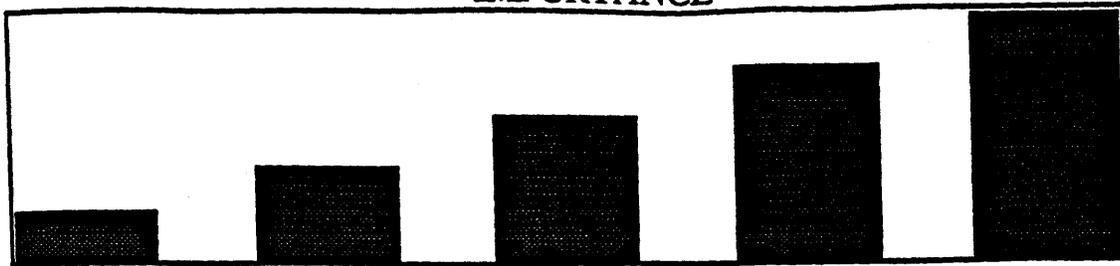
NOT APPLICABLE: NA

The practical things I do

How important to me is -- ?

1. The everyday things I do for a spouse or other adult (laundry, cleaning, etc.).
2. Looking after a pet.
3. Doing volunteer work through an organization.
4. Doing work around my home (cooking, repairs, etc.).
5. Doing work I get paid for.
6. Going to appointments (doctor, dentist, therapist, etc.).
7. Looking after my children or other children.
8. Shopping for myself or others.
9. Helping family, friends, or neighbours in practical ways.
10. Doing school work or course work.

IMPORTANCE



NOT AT ALL
IMPORTANT
1

NOT VERY
IMPORTANT
2

IMPORTANT
3

VERY
IMPORTANT
4

EXTREMELY
IMPORTANT
5

DON'T KNOW: DK

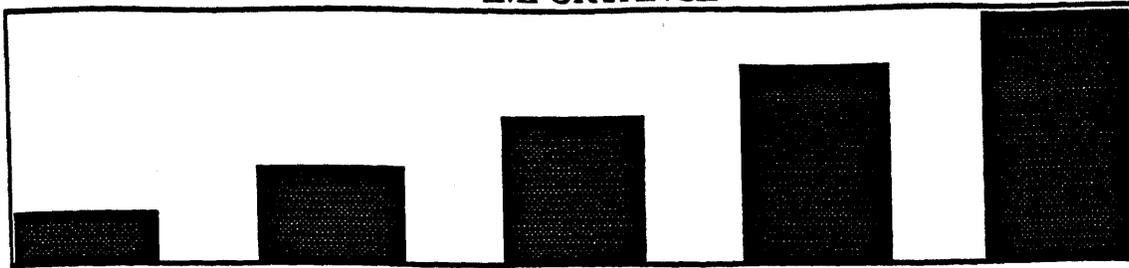
NOT APPLICABLE: NA

The things I do for enjoyment

How important to me -- ?

1. Having vacation and holiday activities. _____
2. Getting out with others (shopping, lunch, etc.). _____
3. Going to community events like fairs or sales. _____
4. Going to movies or shows. _____
5. Doing hobbies (painting, gardening, knitting, etc.). _____
6. Doing indoor activities (TV, reading, etc.). _____
7. Doing outdoor activities (walks, driving, etc.). _____
8. Participating in holiday activities.
(Christmas, Hanukkah, Thanksgiving, etc.). _____
9. Participating in organized recreation activities
(cards, sports, bingo, etc.). _____
10. Visiting and socializing with friends or neighbours. _____
11. Visiting and socializing with people in my family. _____
12. Taking breaks from my usual routines. _____

IMPORTANCE



NOT AT ALL
IMPORTANT
1

NOT VERY
IMPORTANT
2

IMPORTANT
3

VERY
IMPORTANT
4

EXTREMELY
IMPORTANT
5

DONT KNOW: DK

NOT APPLICABLE: NA

The things I do to improve myself

How important to me is -- ?

1. Adjusting to changes in my personal life. _____
2. Creating new challenges and/or projects in my life. _____
3. Improving or maintaining my skills (mental, manual, communication, etc.). _____
4. Improving or maintaining my mental health. _____
5. Improving or maintaining my physical health. _____
6. Learning about new things. _____
7. Learning to get along better with others. _____
8. Solving my own problems. _____
9. Trying things I haven't tried before. _____
10. Sharing ideas with other people. _____
11. Working towards goals I set for myself. _____

II. Satisfaction

Instructions:

The second question to ask yourself is:

How *satisfied* am I with this part of my life?

Another way to think about the question is:

How happy am I with this aspect of my life?

Rate each of the items from 1 to 5, using the rating scale I am giving you now.

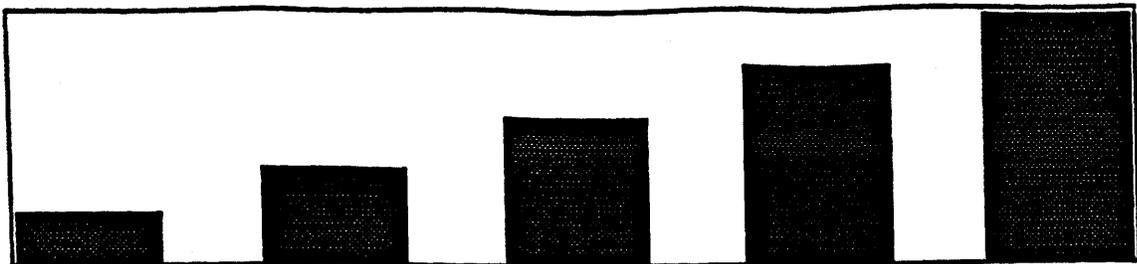
Rate items 5 if you are *extremely satisfied* with these parts of your life; rate items 4 if you feel *very satisfied*. Rate items 3 if you think you are feeling *satisfied* with these parts of your life; rate items 2 if you are *not very satisfied*; rate items 1 if you are *not at all satisfied* with these parts of your life.

Answer each question in terms of your life as it is right now.

Answer each question whether or not you can actually participate in or do the activities described.

If you feel that the question does not apply to you, you would give a rating of "N/A" (Not Applicable).

If you cannot answer the question because you are very unsure, give a rating of "DK" (Don't Know).



NOT AT ALL
SATISFIED

1

NOT VERY
SATISFIED

2

SATISFIED

3

VERY
SATISFIED

4

EXTREMELY
SATISFIED

5

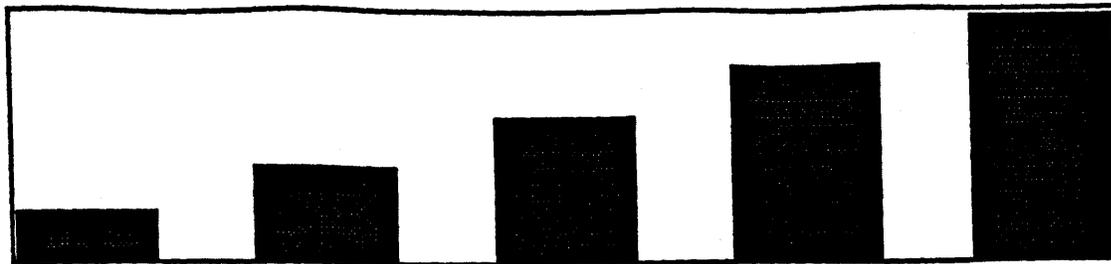
DON'T KNOW: DK

NOT APPLICABLE: NA

My body and my health

How satisfied am I with -- ?

1. My physical ability to get around my home. _____
2. My physical ability to get around my neighbourhood. _____
3. My physical ability to use public transportation. _____
4. How I keep physically active and fit. _____
5. The sleep and rest I get. _____
6. My nutrition and the food I eat. _____
7. The energy I have to do the things I want to. _____
8. How I maintain my personal hygiene and care for myself,
BY MYSELF. _____
9. How I maintain my personal hygiene and care for myself,
WITH THE ASSISTANCE OF OTHERS. _____
10. My personal appearance. _____
11. How I am able to manage the pain that I have. _____
12. My overall physical health. _____



NOT AT ALL NOT VERY SATISFIED VERY EXTREMELY
 SATISFIED SATISFIED SATISFIED SATISFIED
 1 2 3 4 5

DONT KNOW: DK

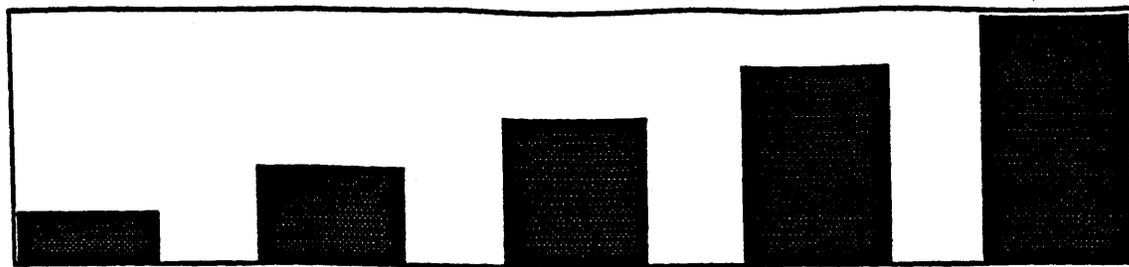
NOT APPLICABLE: NA

My emotional state

How satisfied am I with -- ?

1. How much I accept myself. _____
2. How much I make my own decisions. _____
3. How much I act independently, on my own. _____
4. My ability to remember things. _____
5. How free I am of stress. _____
6. The mood I am usually in. _____
7. How I cope with what life brings. _____
8. How I feel about myself. _____
9. My attitude towards life. _____
10. My sense of humour. _____
11. My mental health. _____

SATISFACTION



NOT AT ALL
SATISFIED
1

NOT VERY
SATISFIED
2

SATISFIED
3

VERY
SATISFIED
4

EXTREMELY
SATISFIED
5

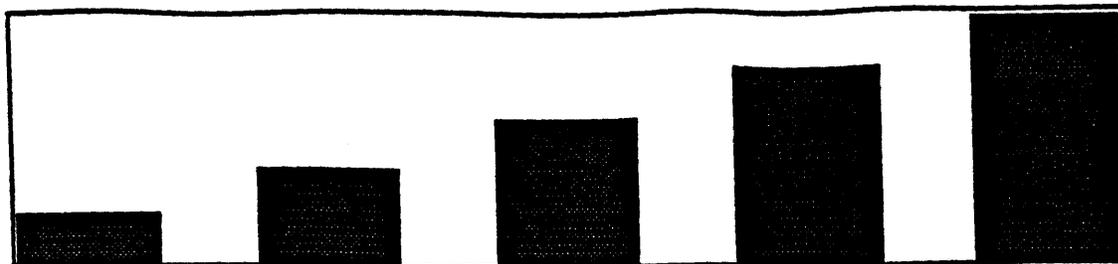
DONT KNOW: DK

NOT APPLICABLE: NA

My beliefs, attitudes and values

How satisfied am I with -- ?

1. How caring I am towards other people. _____
2. How I celebrate birthdays or special events. _____
3. How peaceful I feel within myself. _____
4. How much I feel that my life has purpose. _____
5. How much I share love with other people. _____
6. My own ideas of right and wrong. _____
7. My religious or spiritual beliefs. _____
8. How much I have things to look forward to. _____
9. My participation in religious or spiritual activities. _____



NOT AT ALL
SATISFIED

1

NOT VERY
SATISFIED

2

SATISFIED

3

VERY
SATISFIED

4

EXTREMELY
SATISFIED

5

DONT KNOW: DK

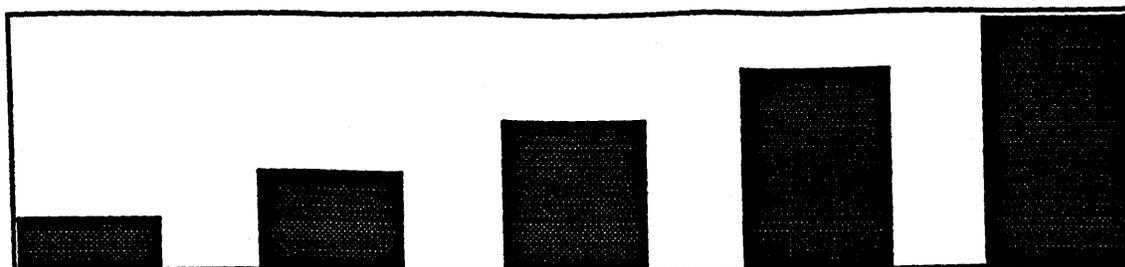
NOT APPLICABLE: NA

Where I live

How satisfied am I with -- ?

1. Where I live. _____
2. The safety of my place. _____
3. The space I have for privacy. _____
4. The personal things I have. _____
5. How comfortable my living place is. _____
6. How much space I have in the place where I live. _____
7. How physically accessible my place is. _____
8. The part of Canada I live in. _____
9. How near I live to my family or friends. _____
10. What neighbourhood I live in. _____
11. How safe my neighbourhood is. _____

SATISFACTION



**NOT AT ALL
SATISFIED
1**

**NOT VERY
SATISFIED
2**

**SATISFIED
3**

**VERY
SATISFIED
4**

**EXTREMELY
SATISFIED
5**

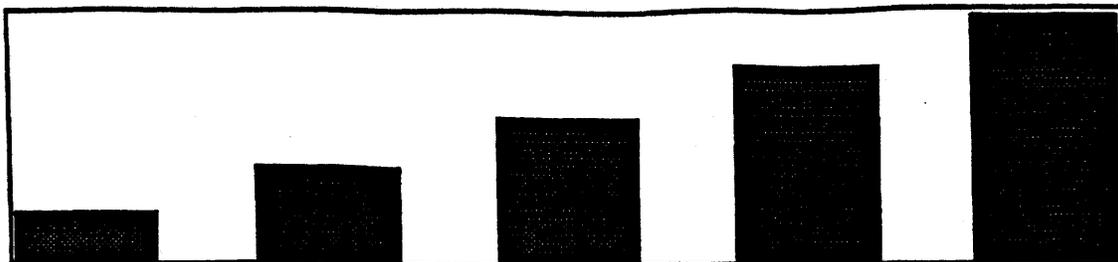
DONT KNOW: DK

NOT APPLICABLE: NA

The people around me

How satisfied am I with -- ?

1. My spouse, partner, or special person. _____
2. My friends. _____
3. How close I am to some members of my family. _____
4. My acquaintances. _____
5. How much I have neighbours I can turn to. _____
6. How much I can count on family members for help. _____
7. My access to people nearby who I can communicate with. _____
8. My involvement in social/cultural/interest/faith groups. _____
9. The degree to which I depend on people in my family. _____
10. The social events I attend. _____
11. How accepted I am by people I see regularly (at work, school, etc.). _____
12. How much sexual intimacy I have. _____
13. How respected I am by people around me. _____



NOT AT ALL SATISFIED NOT VERY SATISFIED SATISFIED VERY SATISFIED EXTREMELY SATISFIED

1 2 3 4 5

DONT KNOW: DK

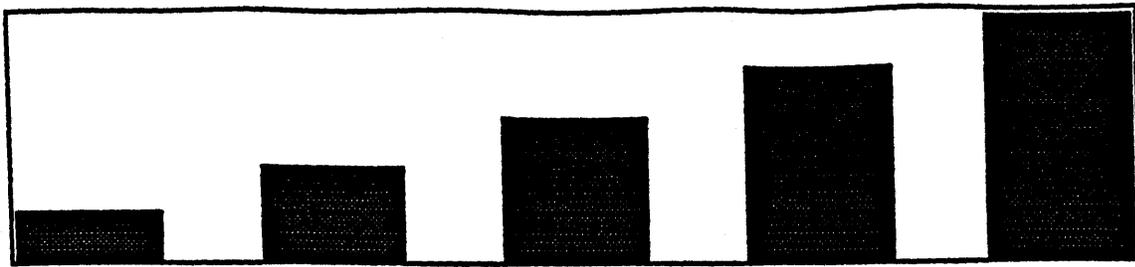
NOT APPLICABLE: NA

My access to community resources

How satisfied am I with -- ?

- 1. How able I am to get health services (from doctors, therapists, nurses, dentists, etc.). _____
- 2. How able I am to get social services (vocational services, social worker, etc.). _____
- 3. How able I am to get other special services (attendant care, etc.). _____
- 4. How able I am to live in affordable housing. _____
- 5. How much I go to neighbourhood places (stores, etc.). _____
- 6. How much the government understands my needs. _____
- 7. My access to meaningful work. _____
- 8. The courses, classes and programs that are available to me. _____
- 9. The amount of money I have. _____
- 10. Events in my community to go to (movies, concerts, etc.). _____
- 11. Programs and services available in a language or form I understand. _____
- 12. The transportation that is available for me to get where I want to be. _____
- 13. The adaptive equipment/resources I have (wheelchair, braille formats, telephone adaptations, etc.). _____

SATISFACTION



**NOT AT ALL
SATISFIED**

1

**NOT VERY
SATISFIED**

2

SATISFIED

3

**VERY
SATISFIED**

4

**EXTREMELY
SATISFIED**

5

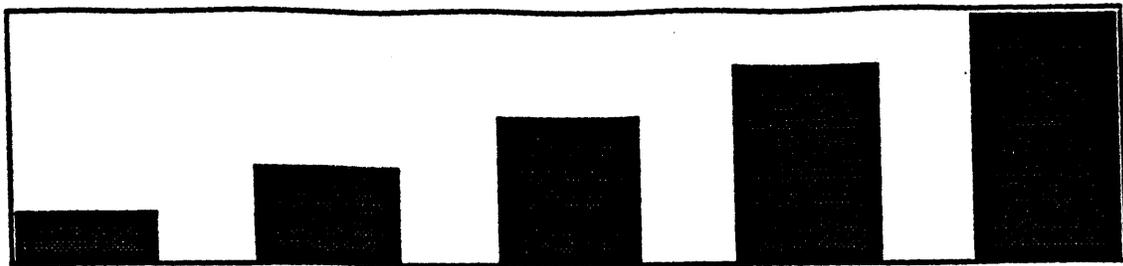
DON'T KNOW: DK

NOT APPLICABLE: NA

The practical things I do

How satisfied am I with -- ?

1. The everyday things I do for a spouse or other adult (laundry, cleaning, etc.).
2. Looking after a pet.
3. The volunteer work I do.
4. The work I do around my home (cooking, repairs, etc.).
5. The work I do that I get paid for.
6. The appointments I have (doctor, therapist, dentist, etc.).
7. The looking after I do for my children or other children.
8. The shopping I do for myself or others.
9. The help I give to family, friends or neighbours in practical ways.
10. Doing school work or course work.



NOT AT ALL
SATISFIED
1

NOT VERY
SATISFIED
2

SATISFIED
3

VERY
SATISFIED
4

EXTREMELY
SATISFIED
5

DONT KNOW: DK

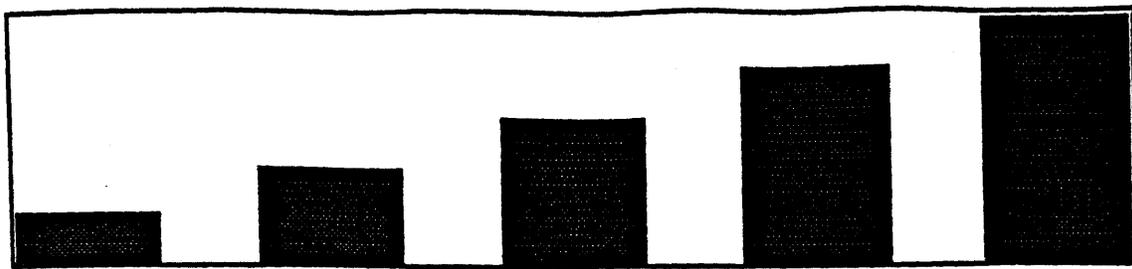
NOT APPLICABLE: NA

The things I do for enjoyment

How satisfied am I with -- ?

1. My vacation and holiday activities. _____
2. How much I get out with others (shopping, lunch, etc.). _____
3. The community events I go to (fairs, sales, etc.). _____
4. The movies or shows I go to. _____
5. My hobbies (painting, gardening, knitting, etc.). _____
6. My indoor activities (TV, reading, etc.). _____
7. My outdoor activities (walks, driving, etc.). _____
8. My holiday activities (Christmas, Hanukkah, etc.). _____
9. My organized recreation activities
(cards, sports, bingo, etc.). _____
10. My visiting and socializing with friends or neighbours. _____
11. My visiting and socializing with people in my family. _____
12. The breaks I take from my normal routines. _____

SATISFACTION



NOT AT ALL

NOT VERY

SATISFIED

VERY

EXTREMELY

SATISFIED

SATISFIED

SATISFIED

SATISFIED

1

2

3

4

5

DON'T KNOW: DK

NOT APPLICABLE: NA

The things I do to improve myself

How satisfied am I with -- ?

1. How I am adjusting to changes in my personal life. _____
2. How I am creating new challenges/projects in my life. _____
3. How I am improving or maintaining my skills (mental, manual, communication, etc.). _____
4. How I am improving or maintaining my mental health. _____
5. How I am improving or maintaining my physical health. _____
6. How I am learning about new things. _____
7. How I am learning to get along better with others. _____
8. How I am solving my own problems. _____
9. How I am trying new things I haven't tried before. _____
10. How I share my ideas with others. _____
11. How I am working towards my own goals. _____

III. Control

Instructions:

The third question to ask yourself is:

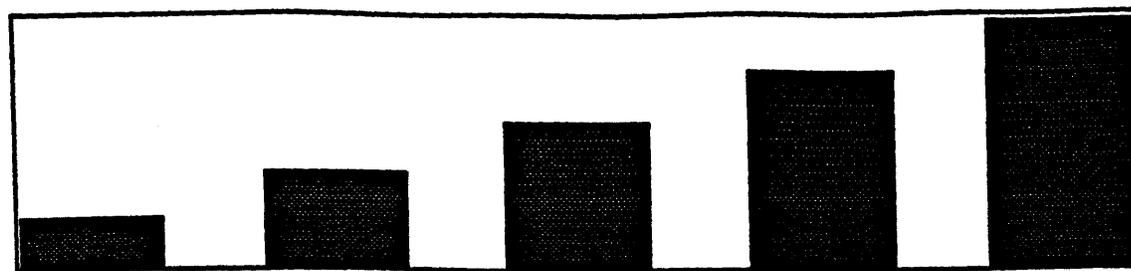
How much control do I have over this part of my life?

Another way to think about the question is:

How much am I in charge of this aspect of my life?

Rate each of the items from 1 to 5, using the rating scale I am giving to you now. Rate items 5 if you have almost total control in this area of your life; rate items 4 if you have much control in this area of your life. Rate items 3 if you think you have about the same amount of control as most people in this aspect of life; rate items 2 if you do not have much control; rate items 1 if you have almost no control in this part of your life.

CONTROL



ALMOST NO
CONTROL

1

NOT MUCH
CONTROL

2

SOME
CONTROL

3

MUCH
CONTROL

4

ALMOST TOTAL
CONTROL

5

DONT KNOW: DK

NOT APPLICABLE: NA

Control

How much control do I have over -- ?

1. My physical health and self-care. _____
2. My thoughts and feelings. _____
3. The spiritual part of my life. _____
4. Where I am living or will be living. _____
5. Who I spend my time with. _____
6. Being able to use what my community has to offer
(transportation, services, resources, etc.). _____
7. The everyday things I can do in my life. _____
8. The things I can do for fun and enjoyment. _____
9. The things I can do to improve myself. _____

IV. Potential Opportunities

Instructions:

The last question to ask yourself is:

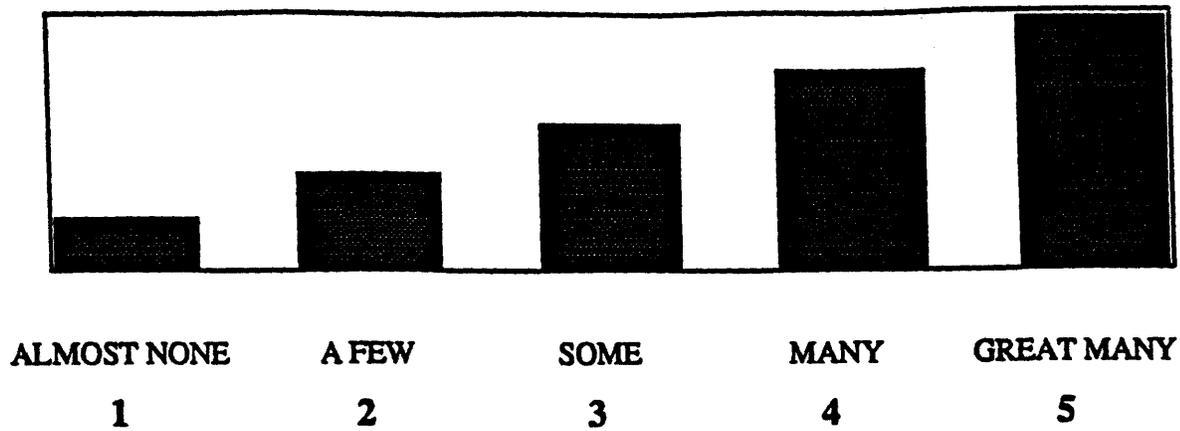
Are there *opportunities* for me to improve or change this part of my life?

Another way to think about the question is:

Are there alternative choices available to me about this aspect of my life?

Rate each of the items from 1 to 5, using the rating scale I am giving you now. Rate items 5 if you have a *great many opportunities* this part of your life; rate items 4 if you have *many opportunities* in this part of your life. Rate items 3 if you think you have about the *same number of opportunities* most people in this part of life; rate items 2 if you have *a few opportunities*; rate items 1 if you have *almost no opportunities* in this part of your life.

OPPORTUNITIES



DONT KNOW: DK

NOT APPLICABLE: NA

Opportunities

Are there opportunities for me to -- ?

- 1. Improve or maintain my physical health and self-care. _____
- 2. Improve or maintain how I think and feel about things. _____
- 3. Improve or maintain the spiritual part of my life. _____
- 4. Live in a comfortable and pleasing place. _____
- 5. Spend time with different people. _____
- 6. Use more of what my community has to offer
(transportation, services, resources, etc.). _____
- 7. Do different daily activities than I do now. _____
- 8. Do different things for fun and relaxation than I do now. _____
- 9. Learn and do new things. _____

WHAT ASSISTANCE DO YOU NEED?

1. How many hours in a typical 24-hour day do you have someone with you to provide assistance?
 hours paid hours unpaid
 _____ assistance _____ (family, others)
2. Not including any regular care as reported above, how many hours in a typical month do you occasionally have assistance with such things as grocery shopping, laundry, housekeeping, or infrequent medical needs like catheter changes?
 _____ hours per month
3. Who takes responsibility for instructing and directing your attendants and/or caregivers?

ARE YOU UP AND ABOUT REGULARLY?

4. On a typical day, how many hours are you out of bed? _____ hours
5. In a typical week, how many days do you get out of your house and go somewhere? _____ days
6. In the last year, how many nights have you spent away from your home (excluding hospitalizations)?
 _____ none _____ 1-2 _____ 3-4 _____ 5 or more
7. Can you enter and exit your home without any assistance from someone? _____ yes _____ no
8. In your home, do you have independent access to your sleeping area, kitchen, bathroom, telephone, and TV (or radio)? _____ yes _____ no

IS YOUR TRANSPORTATION ADEQUATE?

9. Can you use your transportation independently? _____ yes _____ no
10. Does your transportation allow you to get to all the places you would like to go? _____ yes _____ no
11. Does your transportation let you get out whenever you want? _____ yes _____ no
12. Can you use your transportation with little or no advance notice? _____ yes _____ no

HOW DO YOU SPEND YOUR TIME?

13. How many hours per week do you spend working in a job for which you get paid? _____ hours
14. 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
15. How many hours per week do you spend in active homemaking including parenting, housekeeping, and food preparation? _____ hours

16. How many hours per week do you spend in home maintenance activities such as gardening, house repairs or home improvement? _____ hours
17. How many hours per week do you spend in ongoing volunteer work for an organization? _____ hours
18. How many hours per week do you spend in recreational activities such as sports, exercise, playing cards, or going to movies? Please do not include time spent watching TV or listening to the radio.
_____ hours
19. 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

WITH WHOM DO YOU SPEND TIME?:

20. Do you live alone? ___Yes ___No (If yes, skip to question 21.)
- 20a. (If you don't live alone) do you live with a spouse or significant other? ___Yes ___No
- 20b. How many children do you live with? _____
- 20c. How many other relatives do you live with? _____
- 20d. How many roommates do you live with? _____
- 20e. How many attendants do you live with? _____
21. (If you don't live with a spouse or significant other) are you involved in a romantic relationship?
___ Yes ___ No ___ N/A (Subject lives with spouse or significant other.)
22. How many relatives (not in your household) do you visit, phone, or write to at least once a month?
_____ relatives
23. How many business or organizational associates do you visit, phone, or write to at least once a month?
_____ associates
24. How many friends (nonrelatives contacted outside business or organizational settings) do you visit, phone, or write to at least once a month?
_____ friends
25. 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

WHAT FINANCIAL RESOURCES DO YOU HAVE?

26. Approximately what was the combined annual income 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 relatives, and any other source.)
\$ _____
27. 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.)
\$ _____

Appendix 7 – Physical Activity Questionnaire

Leisure Time Exercise Questionnaire

1. Considering a 7 day period (a week), how many times on the average do you do the following kinds of exercise for more than 15 minutes during your free time?.

Times per week

a) Strenuous exercise (heart beats rapidly)

(i.e. Vigorous wheeling, basketball, rugby)

b) Moderate exercise (not exhausting)

(i.e. Fast wheeling, gardening, vigorous housework)

c) Mild exercise (minimal effort)

(i.e. Tai chi, yoga, archery, fishing, housework)

2. Considering a seven day period (a week), during your leisure time, how often do you engage in any regular activity long enough to work up a sweat (heart beats rapidly)?

Circle your response.

Often

Sometimes

Never/Rarely

Godin & Shephard (1985)