

**QUALITY OF LIFE: EXPLORING THE PERSPECTIVE OF PERSONS WITH
SPINAL CORD INJURY**

by

Janice Leanne Beitel

**A thesis submitted in conformity with the requirements
for the Degree of Master of Science
Graduate Department of Nursing Science
University of Toronto**

(c) Copyright by Janice Leanne Beitel 2001



**National Library
of Canada**

**Acquisitions and
Bibliographic Services**

395 Wellington Street
Ottawa ON K1A 0N4
Canada

**Bibliothèque nationale
du Canada**

**Acquisitions et
services bibliographiques**

395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file Votre référence

Our file Notre référence

The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.

The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.

L'auteur conserve la propriété du droit d'auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

0-612-63159-1

Canada

ABSTRACT

QUALITY OF LIFE: EXPLORING THE PERSPECTIVE OF PERSONS WITH
SPINAL CORD INJURY

Master of Science
2001

Janice Leanne Beitel

Graduate Department of Nursing Science
University of Toronto

This descriptive-exploratory study, guided by the human becoming theory, explored quality of life (QOL) for six persons within twelve weeks of traumatic spinal cord injury (SCI). Four themes emerged: 1) resolving to prevail 2) considering alternative views 3) dwelling with enriching affiliations, and 4) bewildering uncertainty. Participants' perspectives shifted post-injury. An awareness that view and approach to life shaped QOL, and the determination to overcome limitations was expressed. Beyond presence, thinking and talking about important relationships contributed to QOL. Uncertainty pervaded the participants' experience. Themes are consistent with research related to the experiences of continuing through difficult times and life altering illnesses. Health professionals may contribute to QOL by facilitating links to important others, by engaging in discussions to surface changing views of a situation, by witnessing the struggle to overcome limitations, and by listening to how others live with uncertainty. Additional research on QOL will continue to build knowledge.

ACKNOWLEDGEMENTS

The author wishes to express gratitude to Dr. Gail Donner and Erin McKenna for their guidance, patience, and scholarly contributions to this manuscript. A heartfelt thank-you to Dr. Gail Mitchell, without whom this undertaking would not have been initiated.

To my colleagues Maureen Starnes and Jan Hess, the “halo” nurses from the Acute Care Spinal Cord Program, my appreciation for the important role they played.

A thank-you must also extend to my family and friends, near and far, for their unfailing support and interest, and for their immeasurable contribution to my own quality of life. For Karl Schroeder and his gift of words, love and laughter, I give a lifetime of thanks.

Lastly, to the men and women who so freely shared their experience, my deepest gratitude.

Table of Contents

CHAPTER

I	Introduction	1
	Quality of Life Research Program.....	2
	Quality of Life for Persons Living with Spinal Cord Injury	2
II	Literature Review	5
	Overview of Research on QOL for Persons with SCI.....	5
	Measuring QOL for Persons with SCI	6
	Major Findings Related to QOL for Persons Living with SCI.....	7
	Summary of Literature on QOL for Persons with SCI.....	11
	Problem Statement	12
III	Methodology	14
	Purposes.....	14
	Theoretical Framework	14
	Protection of Participants	20
	Research Question	21
	Study Design	21
	Research Objectives and Interview Questions	21
	Sample	22
	Data Collection.....	25
	Data Analysis	25
	Data Analysis-Synthesis.....	27
	Analysis-Synthesis: Naming Themes in the Language of the Researcher	27
	Analysis-synthesis: Creating a unitary description of QOL	28
	Credibility and Auditability.....	29
	Limitations.....	31
IV	Presentation of Findings.....	33
	Themes Linked to Research Objectives	34
	Objective One: To Specify the Meaning of QOL for Persons Living with SCI.....	35
	Theme One: Resolving to Prevail	35
	Theme Two: Considering Alternative Views.....	38
	Objective Two: To Identify Patterns of Relating Important to QOL for Persons Living with SCI.....	40
	Theme Three: Dwelling with Enriching Affiliations.....	40

	Objective Three: To Describe Concerns, Plans, Hopes, and Dreams Related to QOL for Persons with SCI.....	43
	Theme Four: Bewildering Uncertainties	43
	Unified Description of Quality of Life.....	45
V	Discussion of Findings	47
	Themes in Relation to Literature on SCI and QOL and Research with Similar Findings.....	48
	Theme One and Related Literature.....	48
	Theme Two and Related Literature.....	52
	Theme Three and Related Literature.....	56
	Theme Four and Related Literature.....	59
	Findings in Relation to the Principles and Concepts of the Human Becoming Theory	63
	Theme One and Two: Resolving to Prevail and Considering Alternative Views	64
	Theme Three: Dwelling with Enriching Affiliations	67
	Theme Four: Bewildering Uncertainties	69
VI	Conclusions, Implications, and Reflections	72
	Conclusions	73
	Implications of Findings.....	75
	Expansion of the Theoretical Framework	75
	Implications for Professional Practice.....	77
	Recommendations for Future Research.....	81
	Reflections.....	81
	REFERENCES	83
	LIST OF TABLES	
	Table A1: Summary of Study Characteristics and Findings Related to Quality of Life.....	97
	Table B1: Glossary.....	112
	Table E1: Core Ideas and Concepts of Resolving to Prevail.....	117
	Table F1: Core Ideas of Considering Alternative Views	120
	Table G1: Core Ideas and Concepts of Dwelling with Enriching Affiliations	123
	Table H1: Core Ideas and Concepts of Bewildering Uncertainties.....	126
	LIST OF APPENDICES	
	Appendix A	97
	Appendix B	112
	Appendix C	114
	Appendix D	115
	Appendix E	117

Appendix F	120
Appendix G	123
Appendix H	126

Chapter I

Introduction

The phenomenon of interest in this research study was quality of life as defined by persons living with spinal cord injury. Quality of life is of increasing interest to researchers, practitioners, and policy makers for a number of reasons, including: advances in life saving and sustaining treatment evoke questions about quantity of years versus quality of years; holistic views of health broaden the definition of health beyond merely physical well being; equality and human rights raise concerns regarding paternalism and how decisions about allocation of resources are made; and economic constraints in health care compel rationing of available resources (Brown, Renwick & Nagler, 1996; McDowell & Nevell, 1987).

In practice, quality of life is of increased importance as it is recognized that health, quality of life, and professional care are interrelated (Calman, 1984; Ferrans, 1990; Gill & Feinstein, 1994; Holmes, 1989; Parse, 1994). Indeed, as an evaluation of outcome, quality of life is used to assess the value of treatment, intervention, and rehabilitation in health care (Brown et al., 1996). Beliefs about quality of life influence healthcare decisions at individual and policy levels (Bach & McDaniel, 1993; Draper, 1991; Gerhart, Koziol-McLain, Lowenstein, & Whiteneck, 1994; Parmenter, 1996). Thus, the way quality of life is defined and evaluated has an impact on persons who enter healthcare systems (Goodinson & Singleton, 1989; Holmes, 1989).

Quality of life is generally viewed as a multidimensional construct and the difficulty in defining and measuring it has been well documented (Butler, 1992; Ferrans, 1990; Gill & Feinstein, 1994; Holmes, 1989; Hughes, 1990; Loew & Rapin, 1994; Brown et al., 1996; McDowell & Nevell, 1987). The definition of quality of life and

whether it is studied by subjective or objective methods reflects the purpose of the research, and the researcher's theoretical and philosophical orientation (Sutcliffe & Holmes, 1991). Regardless of the method, the participant is increasingly recognized as the most appropriate person to provide information on quality of life (Aaronson, 1991; Brown et al., 1996; Calman, 1984; Parse, 1994).

Quality of Life Research Program

This study is part of a larger nursing research program titled: Quality of Life: Exploring the Client's Perspective. The focus of the program is on quality of life as experienced and defined by participants at a major tertiary teaching center. A number of studies from this program have been published (Carson & Mitchell, 1998; Fisher & Mitchell, 1998; Mitchell, 1998; Mitchell & Lawston, 2000; Pilkington, 1999).

The program was guided by Parse's theory of human becoming (Parse, 1981, 1990, 1992, 1994, 1998, 1999). Qualitative methodologies including descriptive-exploratory and phenomenology are employed in the research program. The three objectives of this research program are: to establish a substantive knowledge base about the experience and meaning of quality of life for different groups; to increase knowledge and enhance understanding of specific phenomena linked to quality of life; and to specify directions for program and practice development aimed at enhancing quality of life (Mitchell, Carson, Fisher, Kolodny & Vander Laan, 1994).

Within the program, researchers explored the experience of quality of life for persons receiving inpatient psychiatric care (Fisher & Mitchell, 1998), persons living in long term care (Kolodny, 1996), persons tolerating persistent pain (Carson & Mitchell, 1998), persons living with stroke (Pilkington, 1999), persons living with diabetes (Mitchell, 1998; Mitchell & Lawston, 2000), and persons living with congestive heart

failure (Bourmes, 1997). This current study extended the quality of life research program by exploring the experience of quality of life for persons living with spinal cord injury in an acute care setting.

Quality of Life for Persons Living with Spinal Cord Injury

In North America, 32-35 people per million population suffer a permanent traumatic spinal cord injury (SCI) and survive every year (Canadian Paraplegia Association, 1993; National Spinal Cord Injury Statistical Centre, 1994). Post-injury, individuals spend weeks to months in acute care and rehabilitation centres (Hickey, 1986). Increased survival and life span, combined with the fact that there is no cure for SCI, have stimulated interest in the quality of life experiences of persons living with quadriplegia and paraplegia (Bach & Tilton, 1994; Devivo & Richards 1992; Whiteneck et al., 1992; Noreau & Shephard, 1995). Traumatic SCI has an impact on all realms of a person's existence. Persons surviving can expect a life span that closely approximates that of the general population (Lundqvist, Siosteen, Blomstrand, Lind & Sullivan, 1991). The most frequent age at injury is 19 years, while the mean age at injury is 33.4 years. This means that persons will spend 40-50 years living with paraplegia/quadruplegia (National Spinal Cord Injury Statistical Center, 1994). Quality of life for persons with quadriplegia/ paraplegia is of concern to health care providers, researchers, those who have significant relationships with the person, and for individuals themselves.

Research on quality of life (QOL) with persons living with quadriplegia/ paraplegia is somewhat limited. Research studies have primarily examined the relationship of emotional, psycho-sociological, physical and functional variables to quality of life and life satisfaction (Noreau & Shephard, 1995). Although there is some evidence to support the view that there are unique factors important to QOL for persons

living with quadriplegia and paraplegia, instruments used to measure QOL were adapted from other populations (Bach & McDaniel, 1993; Noreau & Shephard, 1995). It is proposed that prior studies with predefined categories of quality of life may not capture areas important to QOL for persons with quadriplegia/paraplegia (Brown et al., 1996). Although the aforementioned research studies contribute to a general understanding of QOL for persons living with SCI, only two studies were found exploring QOL from the person's perspective (Bach & McDaniel, 1993; Boswell, Dawson & Heininger, 1998).

No studies focused on the QOL as defined by persons with SCI in the acute care setting. In this author's experience, the predominant belief among healthcare providers is that persons with SCI are grieving and adapting during this time, therefore QOL during the acute care phase cannot be captured, or is in such an upheaval that any measure would be unreliable. This viewpoint is echoed in literature depicting stages of adaptation after a spinal cord injury and research proposing QOL as an indicator of adjustment post SCI (Hammell, 1992; Stensman 1994).

If, however, QOL is viewed as a process of shifting values and priorities, then people are continuously experiencing QOL in meaningful ways (Holmes, 1989; Parse, 1994). It is within the weeks and months after the spinal cord injury that individuals with quadriplegia/paraplegia have the most sustained contact with healthcare professionals. There is potential to enhance QOL during these early weeks and months, yet little is known about the QOL of individuals during this time period. If healthcare providers hope to enhance QOL as an outcome or goal, information about the QOL experiences of persons with quadriplegia/paraplegia in the acute care setting is required.

CHAPTER II

Literature Review

This chapter presents a review of the literature related to quality of life (QOL) for persons with spinal cord injury (SCI). The first section of the review provides an overview of the research and identifies several limitations regarding the instruments used to measure QOL. The second section summarizes the findings and provides evidence of unique factors contributing to QOL for persons living with SCI. The third section highlights the gaps and limitations of the literature, supporting the need for the current study. Lastly, a problem statement is offered.

Overview of Research on Quality of Life for Persons with SCI

A comprehensive search and review of the literature was conducted on MEDLINE and CINAHL from 1980 to the present. Relevant references from selected studies were also reviewed. QOL was used interchangeably with life satisfaction in a number of studies and actually was defined as satisfaction with life in one study (Boswell et al., 1998; Kreuter, Sullivan, Dahllof, & Siosteen, 1998; Krause, 1997; Krause & Kjorsvig, 1992; Lundqvist, Siosteen, Blomstrand, Lind & Sullivan, 1997; Post, van Dijk, van Asbeck & Schrijvers, 1998; Prince, Manley & Whiteneck, 1995). As a result, life satisfaction was included with QOL in the review of the literature.

The majority of studies on QOL for persons with SCI were published in the latter part of the last decade, with two thirds of all studies situated in the United States. Almost all employed descriptive or correlational methodologies and report variables present with participants reporting high or low QOL/satisfaction. Two qualitative studies focused on the definition of QOL for the participants and/or the contributing or

influencing factors for QOL (Bach & McDaniel, 1993; Boswell et al., 1998). The characteristics and major findings of the studies are summarized in chronological order in Appendix A. Studies exploring QOL/life satisfaction for persons living with SCI were quite diverse making comparison difficult. For example, the amount of time elapsed since injury varied from 14 weeks to over 20 years. Only four studies, one including a rehabilitation subgroup, involved participants injured less than one year at the time of the study. Not one study took place in the acute care setting. Focus and purpose of studies varied, as did the QOL/life satisfaction measures employed. Instruments used to measure QOL/life satisfaction and the resulting limitations are elaborated on below.

Measuring Quality of Life for Persons with SCI

Concerns related to reliability and validity of the instruments were identified in a majority of the reviewed studies on QOL. Issues included: 1) eleven of the studies did not define quality of life, making it impossible to assess whether the instrument measured quality of life as defined by the researcher; 2) ten studies used an investigator instrument with no report of reliability or validity; 3) five studies modified existing instruments, for example, dropping 6 items from an oncology Quality of Life Index (Nieves, Charter & Aspinall, 1991; Padilla & Grant, 1985); and, 4) some studies using existing instruments stated reliability and validity of instruments established with other populations, however no studies reported reliability and validity with persons with SCI.

Instruments originally designed for other populations may be strengthened by providing an opportunity for participants to identify important aspects of QOL or life satisfaction, and/or to supplement items offered by the investigator (Gill & Feinstein, 1994). However, only two of the studies did so. Eleven investigators provided an

opportunity to provide an overall rating of QOL or life satisfaction, useful with complex concepts like QOL as individuals may be dissatisfied with an aspect of their life, but it may not greatly impact overall satisfaction or QOL (Gill & Feinstein, 1994).

None of the QOL/life satisfaction instruments were developed specifically for use with persons with SCI. The aforementioned fact is a concern given mounting evidence that what constitutes QOL for persons with SCI is different than non-spinal cord injured persons (Bach & McDaniel, 1993; Bach & Tilton, 1994; Gerhart, Koziol-McLain et al, 1994; Kannisto & Sintonen, 1997; Lundqvist et al, 1997; Stensman, 1994; Whiteneck, et al, 1992). Research specifying the unique constituents of QOL for persons living with SCI were derived from descriptive methodologies, or studies that provided an opportunity for the participants to supplement or rate items. The present study enhances understanding of the experience of QOL as described by research participants and the findings add to the knowledge base about QOL/life satisfaction for persons living with SCI. The existing knowledge base about QOL/life satisfaction for persons with SCI is summarized in the section below.

Major Findings Related to Quality of Life for Persons Living with SCI

Despite the diversity of studies, findings consistently support links among variables regarding relationships, health, life management, and QOL/life satisfaction. Inconclusive findings exist between QOL/life satisfaction and variables involving occupation status, age, and time elapsed since injury. Unique factors found to contribute to QOL/life satisfaction for persons with SCI are included in this section and discussed last.

The link between QOL/life satisfaction and relationships is well established (Bach & McDaniel, 1993; Bach & Tilton, 1994; Clayton & Chubon, 1994; Crewe & Krause, 1988; Fuhrer, Rintala, Hart, Clearman & Young, 1992; Kreuter et al, 1998; Post, de Witte, Floris, van Asbeck, van Dijk, & Schrijvers, 1998; Post, van Dijk et al., 1998; Siosteen et al., 1990; Warren, Wrigley, Yoels & Fine, 1996; White, Rintala, Hart & Fuhrer, 1993; White, Rintala, Hart, Young & Fuhrer 1993). Closeness to family, marriage, social support, activity, and integration correlated positively with higher QOL/life satisfaction (Bach & Tilton, 1994; Clayton & Chubon, 1994; Kreuter et al., 1998; Post, de Witte et al., 1998; Siosteen et al., 1990; Fuhrer et al., 1992). Several studies support the importance of relationships to QOL/life satisfaction as rated by persons with SCI (White, Rintala, Hart & Fuhrer, 1993; White, Rintala, Hart, Young & Fuhrer, 1993). Areas of greatest satisfaction included contacts with friends and acquaintances, as well as partnership and family relationships (Post, de Witte et al., 1998; Post, van Dijk et al., 1998). Although the above findings clearly establish links among family, relationships and QOL, no further insight is shed on how or what relationships contribute to overall QOL.

The lack of consistent definition of variables and how each contributes to QOL was evident throughout the studies reviewed. Health, for example, was not defined although it was rated as the most important life area, and identified as influencing QOL/life satisfaction in qualitative and quantitative studies for persons with SCI. (Anke, Stenehjem, & Stanghell, 1995; Bach & MacDaniel, 1993, Fuhrer et al., 1992; Kreuter et al., 1998; Lundqvist et al., 1991; Post, de Witte et al., 1998; White, Rintala, Hart, & Fuhrer, 1993; White, Rintala, Hart, Young, & Fuhrer, 1993). In more recent years, health related quality of life measurements have been investigated in relation to aging and

timing of injury. Unfortunately, the instruments do not provide the opportunity for the participants to describe how health contributes to overall QOL (Kannisto & Sintonen, 1997; Kannisto, Merianto, Alaranta, Hokkanen & Sintonen, 1998). Related to health, life satisfaction has been linked with mortality. Over an 11 year span participants expressing more satisfaction in their lives were significantly more likely to have survived (Krause, Sternberg, Lottes & Maides, 1997).

Although it is known that life management variables such as perceived control, self-care management, and income positively correlated with QOL/life satisfaction, it is not known how the aforementioned variables enhance QOL/life satisfaction for persons living with SCI (Boswell, et al., 1998; Carlson, 1979; Clayton & Chubon, 1994; Crushman & Hassett, 1992; Fuhrer et al., 1992; Lundqvist, et al., 1991; Prince et al., 1995). Finances were rated fourth in importance by both men and women with SCI and were a prevalent theme in a qualitative study with persons with quadriplegia (Bach & McDaniel, 1993; White, Rintala, Hart & Fuhrer, 1993; White, Rintala, Hart, Young & Fuhrer, 1993).

Understanding how different variables contribute to overall QOL becomes valuable in light of contradictory findings. For example, contradictory evidence exists as to whether there is a significant correlation between QOL/life satisfaction and employment status, occupation or job for persons with SCI (Crushman & Hassett, 1992; Clayton & Chubon, 1994; Lundqvist et al., 1991, Westgren & Levi, 1998). Although productivity/activity and opportunities to contribute and create have been identified as important, the opportunity to contribute and create in meaningful ways may or may not be related to employment (Bach & McDaniel, 1993; Boswell et al., 1998). Further exploration on this matter is required.

Other variables requiring further research to understand the relationship with QOL/life satisfaction include time elapsed since injury and age. In several studies, years since injury was positively correlated with higher reported QOL/life satisfaction (Nieves et al., 1991; Pentland, McColl & Rosenthal, 1995). In contrast, findings in three separate studies concluded; 1) elapsed time since injury was not significantly correlated with global QOL (Kreuter, et al., 1998), 2) QOL/life satisfaction decreased over a 10 year period in a sample of persons with SCI (Krause, 1997); and 3) QOL/life satisfaction correlated negatively with persons older than 35 at time of injury (Stensman, 1994). Two possible rationales for the contradictory findings were found in the literature. Firstly, persons injured in childhood (<20) rated health related quality of life higher than those injured in adulthood (Kannisto et al., 1998). Secondly, as persons with SCI age and require more assistance, overall QOL decreases (Gerhart, Berstrom et al., 1993; Whiteneck et al., 1992).

Although contradictory findings identify the need for further research and clarification, it is increasingly clear that there are unique contributing factors to QOL for persons living with SCI. Indeed, the lack of significant correlation between QOL/life satisfaction and variables including: level of injury, completeness of injury, physical function, disability and ventilator dependency, supports the notion that QOL/life satisfaction may be comprised of different elements for persons with SCI (Bach & Tilton, 1994; Crushman & Hassett, 1992; Dunnum, 1990; Kreuter et al., 1998; Lundqvist, et al., 1997; Nieves et al., 1991; Post, van Dijk et al., 1998; Siosteen, et al., 1990; Westgren & Levi, 1998; Whiteneck et al., 1992).

In a qualitative study with persons with quadriplegia, two out of the seven categories of responses in the findings had not previously been described as important to

QOL/life satisfaction in the general population (Bach & McDaniel, 1993). The first new category in the findings was *assertiveness*. This category included speaking up for one's self and asking for assistance when needed. The second new category, not previously identified as important to QOL was the paradox of *dependence/independence*. This category of responses included relying on the assistance of others, while continuing to do as much as possible independently. The paradox of *dependence/independence* was substantiated by Kreuter, et al. (1998) who found perceived loss of independence was significantly correlated with lower QOL scores.

Persons with SCI ranked needs and assigned different weights to the importance of life areas as compared to the general population (Kannisto & Sintonen, 1997; Whiteneck, et al 1992). In two studies, healthcare providers consistently rated QOL for persons with SCI lower than the persons themselves rated their QOL (Bach & Tilton, 1994; Gerhart, Koziol-McLain et al, 1994). When persons with SCI were asked to rate their QOL relative to their same age peers without injury, participants rated it as good as peers or better (Crushman & Hassett, 1992).

Findings from a qualitative study conducted by Boswell, et al. (1998) identified for the first time in the literature that the spinal injury itself was described by participants as a catalyst that changed their perspective of QOL. Participants of this study also identified perception of QOL as fluid, changing throughout life. Further to the importance of the study is the identification of *attitude toward life* as the most significant (as defined by the participants) life domain influencing QOL.

Summary of Literature on Quality of Life for Persons with Spinal Cord Injury

Despite the collection of data supporting correlation among a variety of variables and QOL/life satisfaction, information about what enhances QOL for persons with SCI

remains somewhat elusive. The direction of the correlation between specific variables and QOL cannot be identified (Boswell et al., 1998, Dijkers 1996, 1997). Further, it is unclear how the correlated variables contribute to, or influence QOL for persons with SCI. Insight into what contributes to, and influences QOL may also help to clarify and explain inconclusive and contradictory findings regarding the correlation with occupation status, age, and time elapsed since injury.

Given that there is evidence that what constitutes QOL varies in importance and content among different populations, there is limited information regarding what unique features constitute QOL for persons with SCI. Living with a SCI shapes one's perspective of QOL beyond the obvious limitations the injury imposes on daily life. Instruments originally developed for use with other populations, or that measure other constructs are insufficient to identify what is important to QOL for persons with quadriplegia/paraplegia.

QOL for persons with SCI prior to fourteen weeks post injury has not been researched. The majority of the participants in the studies reviewed were one year or more post injury. Only one study took place in Canada, and only one study utilized a nursing framework.

Problem Statement

Currently, the QOL for persons with SCI in the acute care setting is unknown. Understanding what constitutes and contributes to QOL for persons with SCI is essential as nurses and other health professionals play a major role in persons' lives for weeks and months following SCI. There is little known about what constitutes QOL for persons living with SCI in the time following the injury. More knowledge of what enhances

QOL will enable nurses and other health professionals to contribute to QOL in a meaningful way for persons living with SCI.

CHAPTER III

Methodology

Quality of life as defined by persons living with spinal cord injury (SCI) was the phenomenon of interest in this research project. A descriptive-exploratory design, guided by Parse's (1981,1990,1992, 1994, 1998, 1999) human becoming theory (HBT) was used to gather data that led to the development of themes about QOL for persons with SCI. An overview of the purpose, theoretical framework, research question, and objectives which guided this study are provided in this chapter. Measures to protect participants, design, sample, data collection techniques, and measures to ensure credibility and auditability are also presented. Lastly, the limitations of the current study are discussed.

Purposes

The primary purpose of this qualitative investigation was to describe persons' perspectives of QOL when living with SCI in the acute care setting. Secondary purposes included a) to enhance understanding of QOL issues for additional study, b) to specify practice approaches aimed at enhancing QOL for persons with SCI, and c) to expand the guiding theoretical framework, the HBT.

Theoretical Framework

The aim of qualitative research is to enhance understanding about the experiences of persons, from their perspectives, as they live life situations (Elliot, Fischer & Rennie, 1999). To achieve this aim, qualitative researchers employ a variety of approaches and work within differing explicit and implicit philosophies (Denzin & Lincoln, 1994; Elliot, Fischer & Rennie, 1999; Leininger, 1985; Parse, Coyne & Smith,

1985). Although qualitative researchers acknowledge that research is value-laden (Mitchell, 1994; Denzin & Lincoln, 1994; Janesick, 1994; Haldemann, 1993), the extent to which the researcher's paradigm influences research is debated (Elliot, Fischer & Rennie, 1999; Morse, 1992, Morse, 1994).

Various scholars have argued that all research is inherently theory driven (Crothers & Dolecki, 1989; DeGroot, 1988; Denzin & Lincoln, 1994; Giorgi, 1985; Haldemann, 1993; Mitchell, 1992, 1994; Parse, Coyne & Smith, 1985). According to these authors, explicitly presenting the theoretical orientation and anticipations of the researcher enables others to logically and critically evaluate research findings. In addition, making the guiding theory explicit helps the reader to interpret and understand the researcher's findings (Elliot, Fischer & Rennie, 1999).

The theoretical framework guiding this research project was Parse's HBT (Parse, 1981, 1990, 1992, 1994, 1998, 1999). The underlying assumptions of the HBT also underpin the research design. The HBT is rooted in the human sciences and focuses on the human being's participative experience with the world (Parse, 1981, 1992). A basic premise of the HBT is that persons freely choose the meaning of life situations as they intentionally participate in the creation of life experiences and evolve in mutual process with the universe (Parse, 1990, 1992, 1998). The human is viewed as an indivisible unity, different than 'holistic' views that include the spiritual, mental, and the physical divisions of a person. Humans are recognized through their unique patterns of relating to the universe (Parse, 1992).

Based on the underlying assumptions, research guided by the HBT is necessarily qualitative and focuses on participants' descriptions of lived experience as the primary

data (Bournes, 1997). This perspective assumes that persons are able to accurately represent their personal experiences and research is an intersubjective process in which the researcher seeks better understanding of persons' realities as lived (Pilkington, 1997). The assumptions of the HBT are discussed in more detail below. A glossary of terms is provided in Appendix B for further clarity.

The assumptions underlying the HBT inform three principles (Parse, 1981, 1998). The three principles of the HBT and the theme associated with each principle are as follows:

1. Structuring meaning multidimensionally is cocreating reality through the languaging of valuing and imaging.

Principle one relates to the way human beings continuously structure meaning of multidimensional experiences occurring all-at-once (Parse, 1981). The theme of principle one is *meaning*.

2. Cocreating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing and enabling-limiting while connecting-separating.

Principle two is about the way all human experience is inherently paradoxical and rhythmical in nature. The theme associated with principle two is *rhythmicity*.

3. Cotranscending with the possibles is powering unique ways of originating in the process of transforming.

Principle three is related to the ways humans change in life as they reach beyond the was and is with what is not-yet (Parse, 1981). The theme of principle three is *transcendence*.

Within each principle of the HBT there are three concepts. The concepts within the theory are written as participles and deliberately end in 'ing' to reflect the process orientation of the human becoming theory (Parse, 1992).

Meaning, the theme of the first principle is the personal significance assigned by individuals to life experiences. Three concepts from the human becoming theory are related to the theme meaning: imaging, valuing and languaging. Imaging is the structuring of reality as participants experience the situation in light of the past, present, and future. (Parse, 1998; Pilkington & Jonas-Simpson, 1996). Valuing, the second concept related to the theme meaning, is making choices about what beliefs are, and are not, important. Important beliefs are revealed in the day to day decisions and setting of priorities. Persons are continually choosing and acting on some beliefs while choosing not to act on others (Parse, 1998; Pilkington & Jonas-Simpson, 1996). Languaging is the third concept related to the theme meaning. Languaging is the meaning expressed. This occurs in the ways people tell and do not tell about themselves, their chosen beliefs, and their reality in verbal and non-verbal messages to others.

Rhythmicity is the theme related to the second principle. Rhythmicity reflects the view of seemingly disparate human experiences – paradoxes– as part of the same complex rhythm. For example, hope only exists with no-hope (Parse, 1999). There is no meaning of one without the other and when hope is in the “fore”, no-hope is in the “ground” (Mitchell, 1993). The three paradoxical concepts associated with the theme rhythmicity (principle two) are; revealing-concealing, enabling-limiting and connecting-separating.

The paradoxical rhythm revealing-concealing is related to the choices people make about what to share of themselves, with different people, at different times. The second concept associated with the human becoming theme rhythmicity is enabling-limiting. In making choices, some opportunities are lost and new ones become available. This occurs in every decision a person makes. Connecting-separating is the third concept of the human becoming theme rhythmicity. Humans engage and disengage from others, ideas and ventures, moving in one direction and away from others. (Parse, 1998; Pilkington & Jonas-Simpson, 1996).

Transcendence, the theme associated with the third principle, is moving beyond the present moment. Perspectives shift as what is possible is chosen by a person and actualized. Persons move beyond the now with intended hopes and dreams, to create new ways of viewing the circumstances and situations (Parse, 1981, 1992, 1998). The three concepts related to the HBT third principle and theme transcendence are: powering, originating and transforming. Powering is the pushing-resisting rhythm, the energizing force in the human-universe process. The pushing-resisting force creates tension and opportunities to clarify views. Originating is about choosing individual ways of living that manifest in unique relationships and connections with places, things and projects (Parse, 1992). Transforming is the third concept related to the human becoming theme of transcendence. Transforming is the shift in perspective as the everyday emerges in a new light. As the situation unfolds, participants come to, or discover a new and evolving understanding of life's experiences (Parse, 1998).

The HBT prepares the researcher to look for the meanings, rhythmical patterns, and ways of moving beyond, that people describe in light of their lived experiences. The

person's perspective of life shapes health. In the HBT health is viewed as a process of becoming, a way of living that links values, beliefs, and meanings. It is not adaptation or coping with the environment but rather the way persons live day to day in light of what is important (Parse, 1990). The HBT emphasizes health as a lived experience (Pilkington, 1999).

Quality of life is the goal of nursing in the HBT. QOL is the person's view of living moment to moment in relation to ever changing situations (Parse, 1990). It is not static, but ever evolving in the human-universe process. Quality of life is about relationships, plans, hopes, dreams, and fears. QOL is the "whatness... or the essence of life" (Parse, 1994, p.17). Only the person living the life can describe what constitutes QOL and it is what the person says it is (Parse, 1994). The HBT guides nurses to focus on the meaning of QOL from the person's perspective.

The view of QOL from the HBT is in contrast to other theories that propose QOL can be determined through measurement of emotional, psycho-social, physical and /or functional variables (Parse, 1994). A common view, this author has noted in practice is the belief that persons with SCI in the acute care setting could not possibly know what their QOL is because of the upheaval they are experiencing. Other theories depicting stages of adaptation after a spinal cord injury or proposing QOL as an indicator of adjustment post SCI would attempt to quantify and measure QOL (Hammell, 1992; Stensman 1994).

From the human becoming perspective, QOL occurs in the moment to moment living of priorities that arise from individuals' values and beliefs. This view of QOL provides the opportunity to explore experiences for persons with quadriplegia/paraplegia in the acute care setting. The theory recognizes, acknowledges, and values the person's

experience of QOL at all times. As persons with quadriplegia/paraplegia speak about meanings, relationships, plans, hopes, dreams and fears, they identify what is important to QOL. The HBT was chosen to guide this research because of its concern with the meaning of phenomena as experienced by the person (Parse, 1981, 1992). In addition, QOL from the person's perspective is the goal of nursing in the HBT and is consistent with the purpose of this research.

As a researcher, this author focused on the meanings individuals assigned to QOL; the patterns of relating that influenced quality of life; and the day to day living of hopes, dreams, concerns, and plans. Research findings are organized into themes in the language of nursing science. The themes relate to participants' descriptions of QOL. Consistent with the secondary purpose to expand the guiding theoretical framework, the findings are discussed in light of the principles of the HBT in Chapter 5.

Protection of Participants

This study was approved by the Research Ethics Board of the institution (see Appendix C). Potential participants were informed by a nurse in the Spinal Cord Injury Program that nurses at the hospital were conducting research to learn about experiences of QOL. The researcher met with all participants who indicated interest in participating for the purpose of reviewing the consent form and discussing the study (see Appendix D). The elements of confidentiality and the right to end participation at any time during the study were emphasized. Following a review of the consent form, participants signed the form indicating their informed consent. A verbal consent with a signature by a witness was accepted if clients were unable to sign due to paralysis. A copy of the consent form/information sheet was given to each participant.

Research Question

What is the QOL for persons with SCI in the acute care setting?

Study Design

The method for this study of QOL for persons living with SCI in the acute care setting was descriptive-exploratory. Descriptive-exploratory studies are designed to gain more information about characteristics of the phenomenon of interest. This method was appropriate an appropriate choice as research on QOL with persons living with quadriplegia/paraplegia was limited (Burns & Grove, 1993). Further, the method provides the opportunity to uncover the meaning of phenomena and study the unitary human's participative experience with a situation (Parse, 1998). Specific objectives and questions for data gathering are based on the primary purpose of this research project (to specify the meaning of QOL for persons living with SCI in the acute care setting) and the three themes central to the researcher's theoretical perspective, the HBT (Parse, Coyne, & Smith, 1985). Data for this descriptive exploratory study were analyzed according to the processes outlined by Parse, Coyne, & Smith (1985) and will be expanded upon in the Data Analysis section.

Research Objectives and Interview Questions

The research objectives originate from the three principles and their associated themes of the HBT: meaning, rhythmicity, and transcendence. The three objectives of the study and the related questions guiding the interview were:

1. To specify the meaning of QOL for persons living with SCI in the acute care setting.
 - a) What is most important in your life?
 - b) What does QOL mean for you?
 - c) What enhances quality in your life?

- d) What diminishes quality in your life?
2. To identify patterns of relating important to QOL for persons with SCI.
 - a). Who brings comfort to you?
 - b). How do your relationships influence QOL?
 - c). What is your daily routine like now?
 3. To describe concerns, plans, hopes, and dreams related to QOL for persons with SCI.
 - a. What do you see for yourself in the future?
 - b. What would you like to do to change the quality of your life?
 - c. What are your hopes and dreams?
 - d. What are your concerns about QOL?

Sample

Morse (1994) states that purposeful selection sampling requires the inclusion selection of participants who exemplify the experience being researched, to enable an information rich sample. Participants within four to twelve weeks after a traumatic SCI were recruited from an acute care setting. A review of the literature revealed a lack of significant correlation between QOL/life satisfaction and variables including: level of injury, completeness of injury, physical function, disability and ventilator dependency (Bach & Tilton, 1994; Crushman & Hassett, 1992; Dunnum, 1990; Kreuter et al., 1998; Lundqvist et al., 1997; Nieves et al., 1991; Post, van Dijk et al., 1998; Siosteen et al., 1990; Westgren & Levi, 1998; Whiteneck et al., 1992). As a result, persons with either traumatic paraplegia or quadriplegia were included.

The only other criteria for participation in the study, consistent with the HBT, were that persons wanted to participate and could verbally express their thoughts about the phenomenon of concern in English. The data gathering process was designed to yield

rich and detailed descriptions. Morse (1994) identifies an estimated sample size of six for studies that focus on the meaning of phenomenon. A sample of six participants was proposed for this study and it was felt the quality of the data from six participants would provide enough depth to allow meaningful analysis.

Sandelowski (1995a) suggests that a sample is large enough if researchers feel they have achieved either informational redundancy or theoretical saturation, and cautions that collecting too much data may impede detailed analysis. Further, the HBT assumes that there are universal experiences that transcend details or particular situations. Denzin & Lincoln (1994) concur and argue no individual is just an individual or case. To study the particular is to study the general and it can be assumed that readers will be able to generalize to reflect on their own experiences with the phenomena being studied.

Although the proposed sample size for this research project was six, upon audit of four initial transcripts, an experienced researcher (thesis supervisor) auditing the research process, identified the researcher's initial interviews to be inconsistent with the research method. That is, the conversation was directed by the researcher as opposed to engaging in open questions related to subject of quality of life.

Inappropriate data-gathering and insufficient training of data collectors have been identified by Burns (1989) as a threat to procedural rigor, one of four dimensions of methodological congruence (see measures to ensure credibility and auditability, pg. 26). The initial four transcripts were therefore excluded from the initial data analysis. One additional interview was unusable as a result of poor quality of tape recording. Six additional participants were recruited for the study in order to obtain the intended sample size.

Participants included in the final analysis included 2 women and 4 men. All had sustained a traumatic SCI within three months of participation in the study. All six participants had been transferred to the tertiary health sciences center from community hospitals to be cared for in the Acute Spinal Cord Injury Program. Three participants had a medical diagnosis of paraplegia and three had a diagnosis of quadriplegia. Four participants had spent time in the Critical Care Unit on ventilators before their medical condition stabilized and they were transferred to the Neurosurgical Intensive Care Unit (NICU) step down unit. From the NICU they were transferred to the neurosurgical ward. One participant was admitted to the NICU before transfer to the ward, and the other was transferred from a stepdown unit at a peripheral hospital and admitted to the ward.

Participants' ages ranged between 19-67. Two of the younger participants had not yet established careers, the oldest participant was retired, one was a house wife, one was involved in construction and another, trucking. All interviews took place on the neurosurgical acute care ward, as care routines, tests and participant energy levels prevented interviews prior to transfer to the ward. Rehabilitation applications had been submitted for all participants, and transfer to rehabilitation facilities occurred within two weeks of the interview with the researcher.

Interviews were held in the patient's rooms on the ward. Three of the participants were in private rooms and three were in semi-private rooms. Every effort was made to protect the privacy of the participants. Signs were placed on private rooms requesting not to be disturbed during the interview. For participants in rooms with other patients, strategies to protect privacy included; scheduling interviews while room mates were out of the room and pulling the curtain around the bed and speaking in low voices.

The interviews were tape recorded and transcribed verbatim. Interviews were between 25 and 45 minutes in length. Although an opportunity to continue the interview at another time was offered for each participant, none of the participants chose the option to continue at another time.

Data Collection

Data were gathered through an interview process that was guided by the open ended questions listed under the research objectives previously discussed on page 21-22. The interviews continued for as long as the individuals wished to speak about QOL. As each interview began, the researcher invited participants to talk about what their life was like for them. The researcher followed the person's lead as he/she talked about QOL while seeking as much depth and clarity as possible. For example when one participant offered the following when asked to speak about what is important,

What's important in my life? Number one is family. Number two is probably to succeed in anything I do. Number three is probably just enjoying it... It's going to be different [now] to enjoy life than the way I did, because a lot of my enjoyment was I played many sports. I won't be able to do that now, but I'll still enjoy life.

In response to this description, the researcher asked, "can you say more about still enjoying life?". The researcher continued to invite participants to expand on the ending statement of each response. When participants could not expand further, the researcher asked another question.

Data Analysis

Data for this descriptive exploratory study were analyzed according to the following processes (Parse, Coyne, & Smith, 1985):

1. Reading text of interviews while listening to tape.
2. Identifying and separating major themes contained in text about phenomenon of concern.
3. Relating themes to objectives.
4. Identifying relationships among themes and forming a unified description that captures the QOL experience for all participants.
5. Themes from the language of the subjects are abstracted to the language of the researcher's guiding theoretical perspective.
6. Interpreting and discussing findings in relation to nursing science and in relation to knowledge from other disciplines.

The researcher listened to interview tapes while reading and reviewing the typed transcripts. While reflecting on the participants' experiences, the researcher identified core ideas that could potentially be themes and noted these in the margins of the transcripts. For example, when asked what was important in his life a participant replied "Family support, first and foremost. I've had a tremendous amount of it. It's most gratifying." The core idea of "family support gratifying" was noted in the margin. Another participant stated, "I don't like to fail at anything. I don't think I've ever truly failed at anything, because I'm very persistent. But I mean, I've had to overcome a lot of hurdles in business, work, sports." In this instance the core idea "persistence in overcoming hurdles" was written in the margin.

After analyzing all the transcripts in this manner, core ideas common to all the participants' transcripts were grouped together to form a theme. For example, core ideas about relationships, with how and what relationships contributed to QOL were grouped

together and linked with a research objective. Examples of core ideas from participants contributing to each theme are in Appendices E-H.

After the data analysis of the last six transcripts, the initial four transcripts were examined to determine if the findings were present. Analysis revealed the explicit differences in the richness and depth of the first four transcripts compared with the six analyzed for the themes presented here. For instance, in one of the first four transcripts, although the last statement a participant made was about viewing the physical abilities he had maintained as positive, the researcher ignored this and asked about a thought expressed in the first exchange of the dialogue, e.g. "you mentioned earlier about the importance of having one special person. Can you tell me more about that?" To be consistent with the guiding theoretical framework the HBT, this researcher should have invited the participant to tell more about viewing the physical abilities he had maintained as positive, the last statement he made, rather than picking out a statement he had made earlier and asking him to comment on it.

Data Analysis-Synthesis

Analysis-synthesis is a process of separating the themes according to the major elements in the objectives, examining these elements, and constructing a unified description of the phenomenon as lived by the subject (Parse, Coyne & Smith, 1985).

Analysis-synthesis: Naming Themes in the Language of the Researcher

Consistent with the scientific process of the descriptive-exploratory method explained by Parse, Coyne & Smith (1985) the four themes were synthesized and named in the researcher's language. Words used in researcher's language serve to capture the experience of all participants. For that reason, words the participants chose, such as

relationship, gratifying, support and hope, are not used in the theme name. This shift of language to a higher level of abstraction moves the description of the meaning of the researched phenomenon from the language of the participant to the language of science through the conceptual framework and belief system of the researcher (Ayres & Poirer, 1996; Giorgi, 1985; Haldenmann, 1993). Examples of core ideas from each participants contributing to each theme are included in Appendices E-H. This process was repeated with other core ideas common to all participants and resulted in a total of four themes.

Analysis-synthesis: Creating a Unitary Description of QOL

Human science research methodologies are used to study the unitary human's participative experience (Parse, 1998). Burns (1989) identified descriptive vividness as an indicator of the credibility of qualitative research. This includes providing readers an opportunity to understand the phenomenon under study as a whole experience. From the HBT experiences are lived all-at-once. Pilkington & Jonas-Simpson state:

Each person is continuously structuring meaning, while living the was, is and will be. The realms of meaning are one's personal reality cocreated with one's predecessors, contemporaries, and successors through connections with persons, works of art, music, the media, and in many other ways (1996, p. 19).

Consistent with this view, a unified description that captures the QOL experience for all participants was synthesized from the themes in the findings.

During data-analysis, the researcher identified relationships between the emerging themes. For example, the theme of "how and what" relationships contributed to QOL permeated through all of the data, including the data contributing to other themes. The knowledge of relationships between the themes was used to construct a

unified description of the experience of QOL for persons living with SCI in the acute care setting in the language of the researcher.

The descriptive-exploratory method, as followed in this study, developed only those core ideas shared by all participants. For example, three of the six participants spoke about loss or grieving, however, since loss and grieving was not described by all the participants, it was not included as a major finding.

Credibility and Auditability

Methods to ensure credibility, and subsequently auditability are of importance in qualitative research to assure the reader the research, and therefore the findings, are valid (Ayres & Poirer, 1996). The credibility of qualitative research findings relate to the reader's ability to follow lines of reasoning and to evaluate whether findings are consistent with the guiding framework and the phenomenon under study. The reader of qualitative research should be able to discern how researchers moved up the ladder of discourse from participants' descriptions to the language of science (Elliot, Fischer & Rennie, 1999; Morse, 1994). Burns (1989) developed specific indicators for evaluating qualitative research findings. These indicators guided the researcher in the work and presentation of data. The indicators are as follows:

1. **Descriptive Vividness** - The researcher must present enough detail of the participants, their situation or the context of their living, and their experience as captured in the raw data, to provide readers opportunity to understand the phenomenon as a whole experience.
2. **Methodological Congruence** - The researcher must present the guiding theoretical approach and the chosen method, along with adequate references so that readers can seek more information if desired. The methodological rigor is further identified in four

different dimensions: rigor in documentation, procedural rigor, ethical rigor, and auditability.

3. Analytic Preciseness - This standard is about how researcher move the data from raw description to scientific language. The researcher presents findings so that the reader can follow how decisions were made throughout the analysis.

4. Theoretical Connectedness – “Theoretical connectedness requires that the theoretical schema developed from the study be clearly expressed, logically consistent, reflective of the data, and compatible with the knowledge of nursing” (Burns, 1989, p. 50).

5. Heuristic Relevance - This indicator is about how well the researcher integrates findings into the preexisting knowledge base of nursing. Each nurse who reads the findings should be able to relate to the phenomenon under study and to the findings, at both a personal and professional realm. Further, findings should have some influence in practice, even if only to raise questions.

Auditability, the fourth dimension of methodological congruence (point #2) has eight threats as identified by Burns (1989).

1. Description of data-gathering process is inadequate.
2. Records of raw data were not sufficient to make judgment.
3. Rationale for development of categories or themes is not provided.
4. Researcher failed to develop and/or identify decision rules for arriving at ratings or judgements.
5. Other researchers are unable to arrive at similar conclusions after applying decision rules to data.
6. Researcher failed to record the nature of decisions, data upon which they were based, and reasoning that entered into decisions.

7. Evidence for conclusions is not presented.

8 Theoretical statements are not linked to data.

The indicators outlined by Burns (1989) were observed during the research process. Steps were taken by the researcher to ensure credibility. As previously stated, an experienced researcher (thesis supervisor) audited transcripts to ensure the interview process was consistent with the guiding theoretical framework and research methodology. Further, the researcher maintained all data including original transcripts with margin notes indicating core ideas in the participant's language. A paper trail detailing each of the participant responses contributing to each identified theme was provided for review by the experienced researcher (Morse, 1994).

Limitations

The primary purpose of this qualitative investigation was to describe persons' perspectives of QOL when living with SCI in the acute care setting. Six participant's descriptions lead to the development of four themes that together link to form a unified description of QOL for the participants of this study. The perspective of the researcher assumes that persons are able to accurately represent their personal experiences. The research reported here captures the six participants' perspectives as a single frame in the motion picture of life. Consistent with the HBT, the researcher acknowledges participants' perspectives are continuously changing as meaning is structured and reality is co-created. Marshall & Rossman (1989) state that qualitative research does not pretend to be replicable, nor can it be, because the real world changes.

The six participants in the study were recruited through convenience sampling. Despite this, diversity of participants, including age, occupation, education level was

present. Consistent with the HBT, there is no attempt to generalize the findings of this study to all persons with SCI or prescribe nursing interventions based on the findings. The intent of this research was to increase understanding and the awareness of the experience of QOL for persons with SCI. This process occurs when the research resonates with the reader, that is, the reader judges the material to have accurately represented the phenomenon or to have clarified or expanded their appreciation and understanding of it (Elliott, Fischer & Rennie, 1999). Implications for theory, practice, and future research are discussed in the final chapter.

CHAPTER IV

Presentation of Findings

Quality of life (QOL) as defined by persons living with spinal cord injury (SCI) was the phenomenon of interest in this research project. The objectives of this study, informed by the human becoming theory (HBT), were to: specify the meaning of QOL; identify patterns of relating connected to QOL; and to describe how persons' concerns, plan, hopes, and dreams related to QOL, for persons living with SCI in the acute care setting. A descriptive-exploratory design was used to gather data about QOL for persons with SCI.

Four clusters of core ideas (core ideas common to all participants) emerged from participants' descriptions of QOL. Each cluster was linked with one of the research objectives of the study stated above. The researcher then named the cluster a theme name in the researcher's language to capture the descriptions of all participants. Naming the themes in the researcher's language moves the description of the meaning of the researched phenomenon from the language of the participants to the language of science through the conceptual framework and belief system of the researcher (Giorgi, 1985; Omery, 1983, Parse, Coyne & Smith, 1985, Ray, 1985). This process occurs through the creative abstractions of the researcher (Sandelowski, 1995b). Although the researcher's interpretations are inter-subjective, given the researcher's frame of reference, another person can come to a similar interpretation (Parse, Coyne & Smith, 1985; Sandelowski, 1998). Examples of core ideas from participants contributing to each theme are in Appendix E-H.

The findings are presented in this chapter according to research objective and the themes named in the language of the researcher. After the initial presentation of research objective and the theme(s) linked to it, each theme is discussed separately. Excerpts from the participants' transcripts illustrate conversion from the participants' descriptions to the theme written in the researcher's language. The logic the researcher used is further detailed in the Appendices E-H. The tables provide excerpts from each participant with the extracted core ideas that contributed to each theme respectively.

This chapter concludes with a unified description of the meaning of QOL for persons living with SCI in acute care. This is the last step of the analysis-synthesis process of data analysis as outlined by Parse, Coyne & Smith (1985) and identifies the relationships of the themes to one another, providing the reader with a comprehensive description of the phenomenon as lived by the participants. The unified description answers the research question for the six participants of the study: What is the QOL for persons with SCI living in acute care?

Themes Linked to Research Objectives

The descriptive-exploratory method as outlined by Parse, Coyne & Smith (1985) requires the researcher to develop objectives that link with the guiding theoretical framework. The research objectives of the current study originated from the three central themes arising from the three principles the HBT: meaning, rhythmicity, and transcendence. The three objectives of the study were to: 1) specify the meaning of QOL for persons living with SCI; 2) identify patterns of relating important to QOL for persons with SCI; and, 3) describe concerns, plans, hopes, and dreams related to QOL

for persons with SCI in the acute care setting. The themes are presented below according to the research objective they link with.

Objective One: To Specify the Meaning of QOL for Persons Living with Spinal Cord Injury In The Acute Care Setting

Themes one and two, *resolving to prevail* and *considering alternative views* link with the first objective, the meaning of QOL for persons living with spinal cord injury in the acute care setting. These themes illustrate how participants in the study composed the meaning of QOL through their approach and view of living.

Theme One: Resolving to Prevail

The first theme, *resolving to prevail*, is about how participants' attitude and approach to life influenced the QOL they experienced. Participants made statements such as "I make things possible as I am a positive thinker", and "I am persistent and overcome hurdles." As participants spoke about their outlook and approach to life a heightened determination and will to triumph emerged. One participant stated:

Quality of life, I guess, is mainly what you can put into it, and whatever you can get out of it. I don't think you should expect an awful lot out of it, if you don't put anything into it. I've always given everything I've got and I intend to keep on doing that. Quality of life is living every day as though it's the last one, and keep looking forward to the next one. No great point in looking back; the past is finished, the present counts, and the future is whatever you want to get out of it.

Participants expressed a firm intent to commit all their efforts toward life and living despite limitations. Another participant said,

Quality of life? Quality of life. Hmmm. I guess, for me it's what I put into it, and how I accept things, deal with things, and how people around me adjust, and what I can do to make life better for myself, and what other people can do to help me. If I can do everything in my power, and always put in 110% to what I'm doing, I guess I could improve my quality of life, because even though I'm limited, I still can do a lot of the stuff I could do before.

A third participant shared how she intentionally chose to view quality of life as a challenge.

As I get better, it [quality of life] will probably change... I'm looking forward to a challenge. I guess I see it as that. I have to look at it as that. If I don't, I'm sunk, you know, so maybe it's a challenge too. And it's a blessing, because I get to do one of the things I like to do still - I get to look after my family. So where I take it will depend on me.

For participants, seeing themselves as definers of their experience and being able to do what they enjoyed were ways of prevailing. Another participant stated confidently, What's important in my life? Number one is family. Number two is probably to succeed in anything I do. Number three is probably just enjoying it... It's going to be different [now] to enjoy life than the way I did, because a lot of my enjoyment was I played many sports. I won't be able to do that now, but I'll still enjoy life.

Participants spoke of mastering new abilities and maximizing their potential.

Participants stated they wanted to "get fixed to the best possible", "use the independence we have" and "improve physical abilities the best I can." One participant stated,

I'm working at rehabilitating myself. I've heard all these stories about it's going to be tough. Well, you know what? Life is tough. and [rehab] is just another hurdle, just a bit of a bigger jump, that's all. I'm going to do well over there.

Another participant spoke about being as independent as possible as his goal.

Redeveloping as much movement as I can is another thing that's really important to me. And it's working so far, it's getting better that it was. Any movement that I have is what I get. But I'd like to optimize what I have, so to do as much as I can for myself.

When participants spoke of "doing the best I can", it was not only about physical abilities. Talking about growing as a person, a participant stated,

Well I can't go backwards, and I've got some bets on me, and I've told you how important my family is, and I just can't give up. So I have to go forward. So if I can do that [grow as a person], and then try and reach, you know, as much as I can be then, I'll be happy.

In summary, the theme *resolving to prevail* describes determination and participants' intent to over their limitations, deliberately moving on and continuing with what was important in life. Participants spoke of actively pursuing important aims. Resolving to prevail reveals the resilience and perseverance expressed by participants in light of hurdles, limitations and challenges, while struggling to maximize their personal potential. *Resolving to prevail* links with the first research objective, illustrating how participants' attitude toward life contributes to the meaning of QOL.

Theme Two: Considering Alternative Views

Corresponding to the first theme, the theme *considering alternative views* is connected to the shift in outlook after injury, and how it contributed to the meaning of participants' QOL. *Considering alternative views* links with the first research objective; to specify the meaning of quality of life for persons living with spinal cord injury in the acute care setting. Participants spoke of thinking about things differently and of valuing different things after their injuries. This new perspective influenced participants as they pictured and discussed ways they could choose to be with the differences the SCI would bring to their lives.

Participants made statements such as "I look at it [QOL] in a totally different aspect", and "I think differently about a lot of things." One participant said "I used to take life for granted, and now I cherish life. Now that's its happened, it's over and done with, I find that I cherish life more." Another participant shared the alternative views of life that surfaced since her injury,

The littlest things that I totally took for granted before, now its [a] totally different outlook on the world to have now. Before the accident I've got into like little spiffs with friends, and you hold that grudge for a long time. And then after the accident, who cares about those stupid little things you know? Why would you concern yourself about that, rather than other things?

For the participants, looking at things and seeing things differently, included what they now pictured for themselves, what life might be like. For example, one participant spoke about being in a wheelchair,

I remember thinking that because I'm so active, thinking it must be awful to lose your legs. You know, I don't know what I'd do if I couldn't walk. But I have my arms, I can wheelchair. Knowing me I'll be out there racing, probably.

When thinking about their own lives, participants took into account the experiences of others, shifting how they thought and felt about themselves. One participant stated, "you see the suffering that's going on around you. You say, well, it's no great shakes, but it could have been worse. So on the whole, I count myself as fairly fortunate"

Another participant said "I have so many other riches. I have things that lots of other people don't and those things you can't buy for whatever." Still another participant shared "...I came out with the impression that I'm not that bad, compared to some people and that's kind of uplifting in a way". Thinking about the situations of others altered the participants' feelings about their own circumstances.

Another participant in speaking of alternative views and how he saw himself being with the changes said, "There will have to be a lot of changes, [It's] going to be really rough. There's a lot of things I'm going to have to adapt to. The courage within myself to deal with my problems will be the 'adaption'." Participants thought about ways they could be with life and made statements like "It's not that I am happy, why should I lay in bed? You can't do that, it's how you feel" and "I can lay here and sulk and cry all I want, or I can say, I still got some living to do." Participants expressed an awareness that they could look at the situation in different ways.

In summary, the theme, *considering alternative views*, reflects the shifting viewpoint of the participants in light of their experience with spinal cord injury. This

changing outlook influenced the meaning of QOL for the participants, linking the theme with the first research objective; to specify the meaning of QOL for persons with spinal cord injury. The process of coming to look at and approaching life differently included participants' changing priorities. The participants' descriptions revealed an awareness that the outlook they brought to life influenced the QOL they would experience.

Objective Two: To Identify Patterns of Relating Important to QOL for Persons with Spinal Cord Injury

The third theme *dwelling with enriching affiliations* links to the second research objective, the patterns of relating important to QOL. The theme illustrates how relationships contribute to participants' QOL.

Theme Three: Dwelling with Enriching Affiliations

The theme, *dwelling with enriching affiliations* describes a pattern of relating important to QOL for persons living with spinal cord injury. Participants spoke about how important others were to QOL. Others included spouses, girlfriends, parents, children, family members, friends, hospital room-mates, and hospital staff. Through relationships with others participants experienced support, gratification, comfort, and encouragement. These feelings occurred with and without the immediate presence of the other. As participants dwelled upon the significance of others in their life they experienced comfort, support and gratification. *Dwelling with enriching affiliations* was the most prevalent theme in the participants' transcripts.

Participants spoke about what different relationships meant to them and they described how people affected their quality of life. Below a participant explains,

Well, without.. it would have been much harder for me to recover, and it would be much harder for me to live, if the only person I had was myself, and there's nobody there for me. That's what I think. A lot of people live on their own, and have friends, and stuff like that, but I don't know, I think the more people you have around you to support you, the better your quality of life gets. The more you know you're being cared about, then the higher hopes you get. You know that there are people out there who like you or admire you or love you, and it makes you feel better. It improves your quality.

Relationships provided comfort, support and encouragement, expressed in statements like "they [my parents] bring me back up", "they [the staff] gave me hope", and "my kids are my life." The degree to which relationships enhanced the participants' quality of life was evident when participants expressed sentiments like , "I wouldn't want to be without it [my family]", "I wouldn't have done so well if she [my girlfriend] hadn't been there" and "trying to do this on your own would be physically and mentally impossible." One participant shared "I haven't had a lot of quality of life for 2 months, except I had a lot of care and a lot of love from my family. And that's what got me through it."

Another participant shared a way of dwelling with relationships, beyond presence as she reflected on the expressions of support by friends and the comfort those expressions provided.

Well there's different kinds of comfort. Like when my parents come, that's great. Or even if I get a card from somebody, you know. It could be the funniest card in the world and I'll cry. It's 'cause it's so nice.

Beyond how being with important others enhanced participants' QOL, speaking of and thinking about the person and the relationship also evoked feelings which contributed to QOL. Several participants became overwhelmed when speaking of what persons meant to them. One participant speaking about what it was like to find out her relationship with her husband was so strong said "it took my breath away, and it made me very, very happy and warm." Another participant spoke about his childrens' acceptance of him, "now that I've seen how they've responded, I feel a bit more at ease." A third participant spoke about friends, "I've had a lot of friends expressing their feelings, and letting me know that they're pulling for me which is very gratifying." One participant told of how the support from the community since the accident made her feel that she had been successful. "We're well respected in our little community. There's lots of love and support for us. Lots has gone out to my daughter and my husband. So, in some ways, this accident has made me feel successful [in life]."

In summary, the theme *dwelling with enriching affiliations* describes a pattern of relating connected to QOL, linking with the second research objective. The theme captures what various relationships contributed to participants' experience of QOL including support, gratification, comfort, and encouragement. The relationships the participants engaged in were with staff and hospital room-mates in addition to friends and family. Beyond the presence of those with whom the participants had the relationships, reflection on both the existence of the relationship and the quality of the relationship enhanced participants' QOL. The prevalence of the theme throughout participants' transcriptions reveals the importance of relationships to QOL.

Objective Three: To Describe Concerns, Plans, Hopes, and Dreams Related to QOL for Persons with Spinal Cord Injury

The third objective, to specify the concerns, plans, hopes, and dreams related to QOL for persons with spinal cord injury links with the theme *bewildering uncertainties*. The theme links the uncertainty participants experienced while considering the future to QOL.

Theme Four: Bewildering Uncertainties

The theme, *bewildering uncertainties* links to the third research objective; to describe concerns, plans, hopes, and dreams related to quality of life for persons with spinal cord injury in the acute care setting. As participants spoke about their lives, they talked about unpredictability and the related feelings. The theme *bewildering uncertainties* describes the participants' feelings in light of the unfamiliar and unknown.

Participants talked about "being in a forest", things being "a blur", and the future being "a big grey area." In speaking about looking forward to a new life, one participant said, "I have no idea of the amount of involvement I can look forward to." For some of the participants the hospital environment contributed to the feeling of uncertainty. One participant expanded on everything being a blur in the hospital "[Tell you more] about the blur? Well, you watch the clock all day and you don't know where you're going." Talking about his daily routine another participant said "[It's] unscheduled, off balance and basically screwed up." Another participant shared, "There's not enough consistency for me. Some people, they don't need it in their lives. I do, and there's not enough of it in the hospital to make me feel secure and happy."

When speaking of plans for the future, participants expressed that they did not know what it would be like. One participant said

That's a big question mark, because I don't know what's ahead of me. I don't know what my abilities are going to be in the chair. I've never been in a wheel chair before. Quality of life is..., it's something I don't..., it's kind of shadowy for me right now.

Others said that the future was difficult to talk about because of all the unknowns. One participant stated "...the question you ask me is hard to say, because I don't know, I'm not out there yet. I'm still here in [the hospital]. I haven't actually got a taste of the outside world. I've been in hibernation for almost 6 weeks."

Another participant described her questions and fears in the following statements,

[What do I see for myself in the future?], that's a hard question. Basically, I'm just focusing on getting myself up, just getting one thing at a time fixed, you know what I mean? Like I'm totally scared to go to rehab, like totally frightened. But then, I'm totally excited at the same time.

Participants focusing on one thing at a time, or "taking things day by day" and saying "it's day to day" is further reflection of the uncertainty the participants experienced. A participant talked about what he saw for himself in the future and said, Maybe I could do home sales or get a job outside. I don't know exactly what I could do yet. I'll probably be able to decide better after I go to rehab, 'cause they'll give me more options than I have already, so I'll decide then.

When asked what he would like to change about the quality of his life, one participant stated,

I'm not sure right now, because I've never been in this position before...and I don't know what I have to do to change the quality of my life, but all I know is we're going to work at it, and what we have is what we have.

In summary, the theme, *bewildering uncertainties* reflects the perplexity the participants experienced amidst the uncharted and unfamiliar reality of paralysis. The lack of predictability in participants' lives gave rise to feelings of bewilderment and uncertainty about the future. The participants were continuing on with their lives without the confidence of an established image of what life might be. The unknown would only be revealed in life's unfolding for each participant.

Unified Description of Quality of Life

The research question in this study was: What is the experience of QOL for persons living with spinal cord injury? The findings consist of four themes, together forming the unified description of the QOL as part of the analysis-synthesis process of data analysis in the descriptive-exploratory method outlined by Parse, Coyne & Smith (1985). The notion of integration and synthesis of findings into a descriptive structure of the meaning of the experience has been identified by various authors as part of the data analysis process (Giorgi, 1985; Omery, 1983; Parse, Coyne & Smith, 1985, Ray, 1985). The unified description reflects the all-at-once nature of the human experience, recognizing the inherent complexity, overlap, and paradox of lived experience, thereby contributing to the understanding of the phenomenon under study as a whole experience (Parse, 1998).

During data-analysis, the researcher identified relationships between the emerging themes. The knowledge of relationships between the themes is used to construct a unified description of the experience of QOL for persons living with SCI in the acute care setting in the language of the researcher.

The most prevalent theme was *dwelling with enriching affiliations*. Participants' responses contributing to this theme were woven through responses contributing to the other themes. Participants' responses composing the themes *resolving to prevail* and *considering alternative views* were frequently laced together in the participants' statements. The last theme *bewildering uncertainties* tinted participants' experience of QOL. The theme was a subtle undertone or nuance as participants lived day-to-day.

The unified description of QOL for persons living with spinal cord injury is:
Dwelling with enriching affiliations and resolving to prevail while considering alternative views amid bewildering uncertainties.

CHAPTER V

Discussion of Findings

The phenomenon of interest in this study was quality of life (QOL) as lived and experienced by persons with spinal cord injury (SCI) in the acute care setting. Parse's (1981,1990,1992, 1994, 1998, 1999) human becoming theory (HBT) guided the research. The primary purpose of this qualitative investigation was to describe persons' perspectives of QOL when living with SCI in the acute care setting. Secondary purposes included a) to enhance understanding of QOL issues for additional study, b) to specify practice approaches aimed at enhancing QOL for persons with SCI, and c) to expand the guiding theoretical framework, the HBT.

The research question was: What is the experience of QOL for persons living with SCI? It was answered by synthesizing the four major themes that emerged from the participants' experiences into a unified description of QOL. The unified description was: Quality of life is dwelling with enriching affiliations and resolving to prevail while considering alternative views amid bewildering uncertainties.

The interpretive phase of research includes the connection of the findings to the guiding theory and other related literature (Parse, 1998; Sandelowski, 2000). The discussion of the findings in this chapter are in relation to previously reviewed literature on SCI and QOL (Chapter Two), and in light of other research findings that relate with the themes discovered in the study. The discussion of findings in light of literature identified after the development of themes expands the researcher's comprehension of the research findings. In addition, the discussion fosters the development of

recommendations for practice and further research, consistent with two of the secondary purposes of the study.

The third of the secondary purposes for the study was to expand the guiding theoretical framework. To that end, the third section of this chapter discusses the individual themes in light of the principles and concepts of Parse's HBT (1981,1990,1992, 1994, 1998, 1999).

Themes in Relation to Literature on SCI and QOL and Research with Similar Findings

Theme One and Related Literature

Theme one, *resolving to prevail* describes the participants' approach and outlook on life and how it shaped the meaning of the QOL experienced. Participants' responses when asked what QOL meant to them included, " [QOL] is mainly what you can put into it", "for me [QOL] what I put into it" and "where I take [QOL] will depend on me".

Resolving to prevail reflects the participants' determination and will to continue deliberately participating in the creation of their own QOL. Participants spoke of continuing to do what they enjoyed and mastering new abilities to overcome limitations and challenges with statement like "I still will enjoy life", "we're going to work at it [life]" and "I'd like to optimize what I have." Exploration of findings beyond QOL or SCI research with themes similar to the theme *resolving to prevail* in the current study expands understanding of the theme.

The statements of the participants comprising theme one are consistent with the responses of participants in the qualitative study by Bach & McDaniel (1993) previously discussed in Chapter Two. The researchers named this categorized *Inner Strength/Survival* and described this category as responses about the subjects' control

over life, the ability to make the best of life, and the will to live. The majority of statements made by participants in the Bach & McDaniel (1993) study were related to the *Inner Strength/Survival* category. The predominance of responses connected to this category underscores the association between outlook on life and participants' QOL.

The theme *resolving to prevail* further expands findings from the qualitative study conducted by Boswell et al. (1998), also discussed in Chapter Two who identified attitude toward life as the most significant (as defined by the participants with SCI) influence on QOL. In the current study the participant's attitude toward life was woven into their descriptions of what QOL meant to them. The participants in the study by Boswell et al. (1998) described attitude as "the factor in life that allows an individual to move forward despite obstacles" (Boswell et al., 1998, p. 28). The theme *resolving to prevail* in the current study reflects the participants' determination to continue on with, or to achieve, what they personally identified as important, while living with SCI. The findings in the current study support the idea that approach and attitude toward life influence the experience of QOL for each individual.

No other research or literature was found about *resolving to prevail* in a context similar to the current study. However, the related terms persisting, persevering, and perseverance, were included in findings of several qualitative studies. Exploration of findings beyond QOL or SCI research similar to the theme *resolving to prevail* in the current study expands understanding of the theme, facilitating development of recommendations for practice and further research.

Three studies with findings using the terms persisting, persevering, and perseverance were reported in research exploring the lived experience of hope.

Pilkington & Millar (1999) studied the lived experience of hope. The second core concept emerged as *persevering amid adversity*. Participants saw hope as helping them to keep going in difficult and disheartening circumstances. The theme *persevering amid adversity* involved participants' efforts to resist or overcome challenges presented by disconcerting circumstances in life.

Similarly researchers in two other studies on hope identified core concepts that portray how persons find ways to push on while striving for what is most valued. Cody & Filler (1999) described *persisting amid the arduous* to depict how women in a shelter intentionally decided to look for a brighter day in order to survive difficult circumstances. Allchin-Petardi (1999) named a concept *resolute perseverance* to describe how women living with their children worked toward hoped-for goals.

The descriptions of the core concepts of the three aforementioned studies related to the lived experience of hope resemble participants' descriptions of their approach to life in the current study. Statements about hope from participants which reflect this included "I hope to have the strength to keep going, and be the best person I can be" and "...right now I just hope that I can get back to a routine, and normal enough life to look after my wife, and still work and enjoy it the best I can." The studies on hope shed light on how hope sustains persons' approaches and attitudes toward life in difficult and disheartening circumstances.

Deliberate, focused effort and determination were described by participants living with serious illness in other studies akin to the resolve expressed by participants in the current study as they participated in creating their own QOL. *Deliberating persisting* emerged as a core concept describing the concerted effort participants made to continue

on through a difficult time living with ovarian cancer (Allchin-Pertardi, 1998). *Self-determination* emerged as one of the themes in research interviews that supported the positive experiences associated with living with HIV (Dunbar, Mueller, Medina & Wolf, 1998). Determination was also linked with the ability to transform circumstances in long-term illness and perceive the situation as a challenge versus a threat (Finfgeld, 1995). Several of the participants in the current study spoke directly about seeing their situations as a challenge or a hurdle that could be overcome.

In the current study, participants expressed the awareness that they participated in the QOL they experienced through their approach and view of life. The link between approach to life and life outlook is echoed in the three concepts of hardiness posited by Kobasa (1979a, 1979b) including: the belief that individuals can influence life events; a sense of purpose, meaning and involvement in life activities; and, a view of change as normal and an opportunity for further individual development (Kobasa, 1979, 1979b; Kobasa, Madi & Courington, 1981). Three individuals spoke of individual growth experiences related directly to SCI, and three spoke of personal growth they hoped to attain.

No studies linking hardiness with SCI were found and only one qualitative study has been published, therefore, personal descriptions of hardiness were not available to relate to current findings. Other researchers have proposed hardiness is comprised of different concepts or attributes that do not relate to the current study findings (Jennings & Stagers, 1994; Lambert & Lambert, 1999).

Kobasa's (1979a, 1979b) concept of hardiness and Finfgeld's (1995) study of courage illuminate the notion of persons deliberately making choices about how to

approach life. Participants in the current study described a belief of personal influence on their own experience of QOL through their attitude and approach to life. The first theme, *resolving to prevail*, further expands understanding on how persons chose ways to be with difficult situations and how they participate in the creation of their experience of QOL. Participants expressed determination and deliberate intent to maximize personal potential, to meet and overcome challenges, and to strive toward identified hopes and dreams.

Theme Two and Related Literature

Theme two, *considering alternative views* is about the shift in perspective that participants experienced and how it influenced their views of life. Participants made statement like “[I have a] totally different outlook on the world now” and “now that’s its happened, it’s over and done with, I find that I cherish life more.” The theme *considering alternative views* reflects how the meaning of participants’ QOL was shaped by a shift in perspective after injury and the re-evaluation of priorities. Part of this process for participants, included comparing their own situations to others that the participants saw as less fortunate. In addition participants described seeing different ways they could choose to look at life.

The current study findings are congruent with the idea that priorities and perspectives shift after SCI, with different emphasis and values shaping persons’ perceptions of QOL (Boswell et al, 1998; Whiteneck et al 1992). In addition to ranking needs and rating the importance of life areas differently than the general population (Kannisto & Sintonen, 1997; Whiteneck, et al 1992), persons with SCI also evaluated their own QOL differently than health care providers and the same or better than same

aged peers (Bach & Tilton, 1994; Crushman & Hassett, 1992; Gerhart, Koziol-McLain et al, 1994).

Boswell et al. (1998) suggested SCI is a catalyst that alters the perspective of QOL. In the aforementioned study, the experience of living with SCI emerged as a significant (as defined by participants) influence on QOL. Participants' statements composing theme two are consistent with views expressed in the study by Boswell et al. (1998) These participants said living with SCI had positively influenced their QOL (Boswell et al., 1998). Positive influence is consistent with changes evident in several participants' responses in the current study. A participant shared, "And it's [being a paraplegic] a blessing, because I get to do all the things I like to do." In response to the question, 'is there anything that you would change about your quality of life right now', a participant responded, "I have already - to respect other people for what they are. Whereas I never did that before."

Participants, after the SCI, thought about things differently, altering their values and priorities and finding a new appreciation of life. The responses contributing to the second theme, *considering alternative views*, reveals how priorities and perspectives changed. For some participants change in view was experienced when thinking about the important things they could still do and for others it was through comparing themselves to others who were worse off. Alternatively, for several participants priorities and values shifted as they thought about different ways they could be with the situation. One participant said, "I can lay here, sulk and cry all I want, ... or I can say, hey, you've still got some living to do, you know." Another participant said, "I have to keep high spirits and high hopes that something's new over the horizon, medical technology or.. in my

life, or I won't enjoy it as much." Prior to the current study, no literature related to QOL and SCI discussed the process of shifting priorities or that persons think about different ways to be with the situation and chose how to view it. The current study contributes to knowledge on QOL for persons with SCI by illuminating how living with SCI shifts the perspective and outlook on life.

The term *considering alternative views* was not found in any other literature. However, several studies beyond the literature discussed in Chapter Two were found where participants spoke of looking at life differently, re-evaluating life, and shifting priorities. Although the following studies are not with persons with SCI, they do involve life altering illnesses. The participants in the majority of these studies were patients with cancer. Exploring these studies expands understanding related to the findings in the current study.

Redefinition emerged as a theme in one study describing how participants felt that the cancer experience had changed them and that they had redefined their goals and roles (Halldorsdottir & Hamrin, 1996). A new outlook on life and re-evaluated life priorities were identified in two separate studies with women with breast cancer and one study with women with ovarian cancer (Allchin-Pertardi, 1998; Loveys & Klaich, 1991; Pelusi, 1997). Steeves (1992) described a shift in perspective for patients with bone marrow transplantation which included comparing themselves to others who were worse off. Several participants in the current study described viewing their own situation in light of others, acknowledging their situation could be worse and feeling fortunate in comparison.

Changes in life view were found in other studies following life altering illness events, including heart transplantation and stroke (Mishel & MurDaugh 1987; Pilkington, 1999). The findings of these studies highlight how persons re-evaluate priorities, change their outlook on life and experience a shift in their attitudes when experiencing a serious illness.

The ability to see situations in more than one way was found in a study previously discussed. Allchin-Petardi (1999) described *formidable ambiguity* as the core concept reflecting the participants' ability to view their difficult situations in more than one way in a study of the lived experience of hope for women with children. The author states "situations were identified as personally insurmountable and all-at-once surmountable as each participant knew there was more than one way to move beyond" (Allchin-Petardi, 1999 p. 284).

The second theme, *considering alternative views*, includes participants' descriptions of seeing different ways they could be with and/or approach their changing situations. As previously identified the themes *resolving to prevail* and *considering alternative views* were connected in the participants' descriptions and this connection is supported by other literature. *Self-determination*, a theme identified in a study with patients with HIV included participant statements such as "you can either cry about it and wallow in it, or you can try to pick yourself up and enjoy life for what it is" (Dunbar et al., 1998, p. 149).

The idea of choosing to see life in a specific way is consistent with findings emerging from research on courage by Finfgeld (1995). Participants transformed their view of circumstances to be challenging rather than threatening. One aspect of this

included a firm commitment to cognitively convert a struggle into a challenge, implying participants recognized the situation could be viewed in more than one way.

Participants in the current study also described believing that the QOL they experienced was influenced by how they viewed life and what effort they put into it. Each participant spoke of the ability to impact their QOL through their approach to life and how they chose to view the situation. Consistent with this notion, two of the three concepts of hardiness identified by Kobasa (1979a, 1979b) are linked to outlook on life. Control is the belief that individuals can influence life events. Challenge, according to Kobasa, is a view of change as an exciting incentive for further individual development. In the current study several of the participants spoke of maximizing their potential and two spoke of gaining satisfaction through working in the future with SCI groups to provide support and encouragement.

The theme, *considering alternative views*, reveals that persons think about different ways they can be with a situation, view a situation, and influence the QOL they experience through their choices. The research and literature reviewed, describing how persons actively make choices about how to view life situations, sheds some light on the process by which participants experience a change in outlook and a reevaluation of priorities during the experience of serious illness.

Theme Three and Related Literature

Theme three, *dwelling with enriching affiliations*, is about what relationships meant to participants and how the relationships enhanced QOL. Speaking of, and thinking about the person/relationship also evoked feelings which contributed to QOL for the participants. Relationships with others were described as providing

encouragement, humour, hope, gratification, and support to participants' lives.

Participants spoke about spouses, girlfriends, parents, children, family members, friends, hospital room-mates, and hospital staff.

The reports of participants in this study in relation to theme three are consistent with numerous studies that established a link between relationships, support, social activity, and QOL for persons with SCI (Bach & McDaniel, 1993; Bach & Tilton, 1994; Clayton & Chubon, 1994; Fuhrer et al., 1992; Siosteen et al., 1990; Warren et al., 1996). Participants in the current study consistently identified relationships as important with statements such as "What makes my life special? Probably my family", "What's important to my life? Number one is my family" and "[What enhances quality in my life?] Family support." This is congruent with the findings where family relationships were rated high in importance by persons with SCI (White, Rintala, Hart & Fuhrer, 1993; White, Rintala, Hart, Young & Fuhrer, 1993).

In the current study, relationships provided comfort, support, and encouragement. Participants specified how relationships were enriching in statements like "[my parents] bring me back up", "[the staff] gave me hope", and "my kids are my life." The importance and satisfaction participants attributed to relationships, is consistent with findings by Post, de Witte et al. (1998) and Post, van Dijk et al. (1998) where contacts with friends and acquaintances, family life, and partnership relationships were among the areas rated as highest level of satisfaction for persons with SCI.

Although the link between relationships and QOL -- including the importance attributed and satisfaction received -- has been previously established, the current study expands the understanding of how relationships enhance QOL uniquely for each person

with SCI. Relationships brought feelings of gratification, success, humour, inspiration and solace. For each participant, the details about who relationships were with, and how relationships contributed to QOL were uniquely constructed. The feelings and thoughts that relationships evoked happened over distances and through written word.

Participants also provided insight into how life might be if they did not have the relationships. For example, one participant said “it would have been much harder for me to recover, and it would be much harder for me to live, if the only person I had was myself, and there was nobody there for me.”

The third theme of the current study, *dwelling with enriching affiliations*, further expands understanding about QOL through introducing the idea that thinking about and speaking of relationships evokes feelings which influence QOL. The idea has not previously been explicitly identified in the literature related to QOL for persons with SCI and contributes depth to knowledge related to relationships and how they contribute to QOL.

Findings of several other published studies with other populations also expand understanding about ways relationships and important others contribute uniquely to persons' QOL. Connecting current findings with other related literature is an aspect of the interpretative phase of research and contributes to the development of recommendations for practice and further research (Parse, 1998).

Qualitative studies with persons experiencing serious illness identified that relationships with others enabled participants to persevere through difficult times with courage (Allchin-Pertardi, 1998; Finfgeld, 1995). Further, a theme emerging from a study exploring QOL for persons after a stroke, *consoling relationships uplift the self*,

described the difference family, friends and hospital staff made to participants' experience of quality of life (Pilkington, 1999).

In the current study, two participants described staff and family as providing hope, consistent with findings from several studies exploring the lived experience of hope. Participants described relationships with others as providing not only hope, but joy, warmth, happiness, comfort, encouragement, revival, appreciation, gratitude and support (Pilkington & Millar, 1999; Toikkanen & Muurinen, 1999; Wang, 1999; Willman, 1999). The connection between the findings related to the research on hope and the themes of *resolving to prevail* and *dwelling with enriching affiliations* in the current study leads to questions related to the link between hope and the experience of QOL.

The theme *dwelling with enriching affiliations* deepens the understanding of how relationships enhance QOL. Specifically, the findings of the current study illuminates how relationships contribute to QOL, beyond the presence of individuals, through feelings arising when reflecting on or speaking of the person/relationship with others.

Theme Four and Related Literature

The theme *bewildering uncertainties* is about the unpredictability in participant's lives and the related feelings that emerged as participants spoke about "being in a forest", seeing the future as "a big grey area" or "a big question mark." Several participants said that the future was difficult to talk about because of all the unknowns.

The current study contributes to the knowledge of what constitutes QOL for persons with SCI by identifying uncertainty as a factor shaping QOL. Further, the responses of the participants provide insight into strategies participants employ to live

with bewildering uncertainties. For example participants spoke about “just focusing on healing”, “taking things day by day” and “just take it one day at a time.” The findings of this study will serve to increase awareness of the influence of uncertainty on QOL for persons with SCI.

Although uncertainty has not been linked to the phenomenon of QOL for persons with SCI, two research studies explored the concept of uncertainty with persons with SCI. Uncertainty has become an increasingly popular research concept in the past decade. Mishel’s (1988, 1990) uncertainty in illness theory and other qualitative research findings beyond literature on SCI will be discussed in relation to the current study theme *bewildering uncertainties*.

Yoshida (1997) used a grounded theory approach to describe the various forms of uncertainty experienced by people living in the community up to 22 years post-traumatic SCI. The accounts were organized using Conrad’s (as cited in Yoshida, 1997) general categories of uncertainty and the descriptions in the category of *trajectory uncertainty* bear only the slightest resemblance to what participants in the current study expressed. This may be a reflection of the difference in the time elapsed since injury for participants in Yoshida’s research (1-22 years) and the current study (4-12 weeks).

The second study exploring uncertainty and the use of coping behaviors with persons with SCI used Mishel’s (1990) definition of uncertainty, the inability to determine the meaning of illness related events (Wineman, Durand & Steiner, 1994). The original Mishel Uncertainty in Illness scale for acute illness was used, despite the mean time since injury of the participants being 11 years. The study provides little information about the uncertainty persons with SCI experienced. The authors conclude

that participants perceived high levels of illness uncertainty and they used strategies to regulate distressing feelings.

Mishel (1990) reconceptualized the uncertainty in illness theory to allow for the conceptualization of growth and change following the experience of uncertainty and extend the applicability to include chronic illness where many persons live with enduring uncertainty. Four frequent areas of uncertainty are identified with illness: severity of the illness; success of treatment; impact of the illness on one's life; and the ability to pursue lifes' dreams and ambitions (Mishel, 1990). In the current study, participants talked about how the SCI might impact on their lives and what they saw for themselves in the future. Participants were unable to predict what abilities they might have after rehabilitation or what work they might do, contributing to their uncertainty.

Mishel (1990) states that uncertainty results in a new ability to see multiple alternatives and possibilities, and to reevaluate what is important in life. The new view of life develops in interaction with, and exchange between, the person and the environment. Uncertainty may bring about a transition from one perspective. As discussed in theme two, *considering alternative views*, participants in the current study described the shift in thinking in light of their situation and by comparing themselves to others.

Findings of several qualitative studies on the lived experience of persons living with chronic illnesses include uncertainty. Stroke patients expressed uncertainty about how long they would be in hospital, their prognosis, and the possible trajectory of the illness (Close & Proctor, 1999). For patients with ulcerative colitis and rheumatoid arthritis, uncertainty was related to the day-to-day changes in symptoms, making long-

term planning impossible (Dudley-Brown, 1996; Nyman & Lutzen, 1999). Two of the participants in the current study spoke of the unpredictability and inconsistency of their day-to-day routine in the hospital. However, symptomatic unpredictability did not emerge. This may have been a reflection of the time since injury as others have identified issues such as consistency of bowel routine to be important to persons with SCI (McKenna, 1994; Yoshida, 1997).

Reflective of the amount of research in the area, uncertainty has been linked to the experience of living with cancer. Uncertainty about the future and re-occurrence, emerged in three qualitative studies with participants with cancer (Halldorsdottir & Hamrin, 1996; Loveys & Klaich, 1991; Pelusi, 1997). Uncertainty is included in some versions of the City of Hope QOL instrument in research on QOL for persons with breast cancer (Dow, Ferrell, Leigh, Ly & Gulasekaram, 1996; Ferrell, Grant, Funk, Garcia, Otis-Green & Schaffner, 1996). Interestingly, even when it was not included as part of a tool used, uncertainty emerged as a theme in the qualitative data collected with long term survivors of autologous bone marrow transplantation (Whedon, Stearns & Mills, 1995).

Research by Bertero & Eriksson (1997) not only illuminates the link between QOL and uncertainty, but also establishes evidence that the uncertainty persons experience when acutely ill is different than the uncertainty chronically ill persons experience. The researchers found that although the participants with chronic leukemia face uncertainty, there is no immediate life-threatening feeling. For the persons living with acute leukemia, the only certainty is that they are living now. Nothing can be taken for granted. Persons with chronic leukemia described QOL as *life satisfaction*, whereas

adults with acute leukemia described QOL as a *positive attitude to life*. The researchers proposed that “a feeling of uncertainty” was the phenomenon that made the difference to the experience of QOL.

Description of QOL as positive attitude toward life by persons with acute leukemia, (Bertero & Eriksson, 1997) echoes ideas from the current study in the theme, *resolving to prevail*, that is, attitude shapes QOL. Further, it is consistent with Boswell et al. (1998) who identified attitude toward life as the most significant (as defined by the participants with SCI) influence on QOL.

In the current study, the fourth theme *bewildering uncertainties* establishes that uncertainty is experienced by persons living with SCI. The experience of uncertainty and its influence on QOL appears to be different in the acute care setting than the uncertainty experienced several years post injury. Uncertainty in the acute care setting after SCI is unlike the uncertainty experienced with chronic illnesses that have an unpredictable course, periods of symptom exacerbation, or a deteriorating trajectory. No literature was found exploring uncertainty with the general population. The prevalence of uncertainty and the descriptions provided in the research reviewed leads this author to agree with Parse (1999) who proposes uncertainty is inherent in all human experiences. Uncertainty means different things to different people and how it changes life patterns and hopes are important to explore and understand (Parse, 1999).

Findings in Relation to the Principles and Concepts of the Human Becoming Theory

Parse's (1981,1990,1992, 1994, 1998, 1999) HBT guided the research described here. The objectives of this study were to: specify the meaning of QOL; identify patterns of relating connected to QOL; and, describe how persons' concerns, plans, hopes, and

dreams related to QOL for persons living with SCI. The objectives flow from the three theoretical principles of the HBT and the central themes, meaning, rhythmicity, and transcendence. The ultimate purpose of the study was to describe persons' perspectives of QOL when living with SCI in the acute care setting. The unified description of the perspective of QOL for the participants in this study was: Dwelling with enriching affiliations and resolving to prevail while considering alternative views amid bewildering uncertainties.

Although the themes associated with the principles of the HBT; meaning, rhythmicity, and transcendence, are lived all-at-once as reflected in the participants' unified description, individual themes representing the major findings may reflect one principle of the HBT more explicitly than another. The HBT directs researchers to seek the meanings, the patterns of relating, and ways of transcending within the participants' descriptions. Below, themes from the study are discussed in light of the corresponding principle and concepts of the HBT.

Theme One and Two: Resolving to Prevail and Considering Alternative Views

The first and second theme of the study were *resolving to prevail* and *considering alternative views*. These themes link most directly with the HBT theme meaning and principle one; "structuring meaning multidimensionally is cocreating reality through the languaging of valuing and imaging" (Parse, 1981, p. 42). Meaning is the constructing of personal reality through assigning significance to individual experiences (Parse, 1998; Pilkington & Jonas-Simpson, 1996). Participants' attitude and approach to life shaped the meaning of the QOL experienced.

Three concepts from the HBT link with the theme meaning: imaging, valuing and languaging. Imaging is the shaping of reality as participants experience the situation in light of what was, is, and will be. Amid this co-created process of personal knowing and coming to know, ideas or events become real to the participants. Personal knowledge is both utterable, within reflective awareness, and unutterable, being beyond reflective awareness (Parse, 1998; Pilkington & Jonas-Simpson, 1996).

The participants' experiences of QOL were co-constructed and emerged in mutual process with the personal knowledge of what was, is, and will be. One participant shared,

The quality of life, I guess, is mainly what you can put into it, and whatever you can get out of it. I don't think you should expect an awful lot out of it, if you don't put anything into it. I don't. I've always given everything all I've got, and I intend to keep on doing that. Quality of life is living every day as though it's the last one, and keep looking forward to the next one. No great point in looking back; the past is finished, the present counts, and the future is whatever you want to get out of it.

Valuing, the second concept related to the theme meaning, is making choices about which beliefs are, and are not, treasured. Treasured beliefs are lived in the day to day decisions of priority setting. Participants decide what is important in their lives based on personal values, and in turn make choices that reflect their treasured beliefs. Persons are continually choosing and acting on some beliefs while not choosing and acting on others (Parse, 1998; Pilkington & Jonas-Simpson, 1996). Values influenced

participants' approach to life as illustrated in the above excerpt. Priorities shaped participants' attitude. One participant spoke of the importance of her family,

They mean the most. That makes my life worth getting over and getting back to the races. That's why I want to get stronger. I know some people, they think, well who'd want to be paralyzed, and live? But I have my arms, I can wheelchair. And we'll still hike. We do a lot of outdoor things. I can still do all those things. I can take her to gymnastics; I can watch her grow; I can be there for her next graduation when she goes to grade 8, or brings home a boyfriend.

The values the participant held, for example the importance of family, shaped decisions about how to view and approach life.

Languaging, is the third concept related to the theme meaning. Languaging is about expressing meaning through the messages given and not given about one's chosen beliefs and reality. Participants' descriptions contributing to the themes *resolving to prevail* and *considering alternative views* are in themselves messages that participants' chose to reveal about their personal beliefs and reality. The personal beliefs participants expressed about attitude and approach to life shaped the meaning of QOL experienced. Further, participants expressed awareness or belief that attitude and approach to life influenced QOL. "Meaning arises as the fruit of what one chooses to attend to in relation to persons, ideas, objects, or situations. The attended to is the meaning, which is cocreated constructed reality" (Parse, 1994 p. 18). Through their beliefs, attitudes and approaches, individuals of this study participated in the creation of their reality and QOL.

Theme Three: Dwelling with Enriching Affiliations

The theme *dwelling with enriching affiliations* is linked to the human becoming theme rhythmicity and the principle, “cocreating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing and enabling-limiting while connecting-separating” (Parse, 1981, p. 50). Rhythmicity reveals the complexity of human beings as seemingly opposite, patterns of relating are lived all at once. Each relationship, and the manner in which it contributed to participants’ QOL, was unique. Within these relationships, paradoxical patterns related to the desire to be with others and what participants shared with others emerged. Participants expressed seemingly contradictory statements as they discussed possibilities emerging with relationships in light of current events. These paradoxes are evident throughout the participants’ transcripts. The paradoxical concepts associated with the theme rhythmicity are; revealing-concealing, enabling-limiting and connecting-separating.

The paradoxical rhythm revealing-concealing is related to what humans share and do not share with others. Human beings are unfolding mysteries, that cannot be fully known by others (Parse, 1998). How persons are, and how they seem to be is what is disclosed and not disclosed. Participants chose at reflective and pre-reflective realms what they would tell this researcher, staff, family, and friends. Below, a participant talked about the relationship with her best friend, and what she chose and did not choose to tell her friend.

Well, I’m pretty confused, actually, about the whole thing, 'cause my friend was driving. From what I hear, she could be at fault. So I had to come to terms with that. And I talked to her, and she says to me, you know, “Oh, it’s so terrible; I

have to actually get my parents to walk me to the bathroom door." You know, and I just feel like saying, 'At least you can go.' But I know because of that injury [mild traumatic brain injury], she doesn't have all the feeling there."

The second concept associated with the human becoming theme rhythmicity is enabling-limiting. This paradox means that in the process of making choices, some options are lost and some new ones are gained. As participants talked about the possibilities that lay ahead, present alternatives were both curbed and spawned by previous choices. One participant expressed "...the one regret I don't have, the one regret I do have is that we didn't have children. But now I wouldn't want any. I don't think it'd be fair to my wife to have to look after me and look after a child." If an earlier decision was made and children present, this would no longer be a choice to make.

A further illustration of this paradoxical rhythm of opportunities and restrictions is present as one participant talked about the drawbacks and benefits of living in a rural community.

For one thing, living rurally like we do, I'd have more available to me [resources] if I lived in Toronto... I still think living rurally, on the other hand, will give me a peace, that maybe some paraplegics don't have; that I have a community. And it's very beautiful.

Connecting-separating is the third concept of the human becoming theme, rhythmicity. Humans engage and disengage from others, ideas and ventures, moving in one direction and away from others all-at-once. Illustrations of connecting and separating with others are present in participants' descriptions. Another participant shared, "[there were] a few days where I was just in a terrible mood. And even the fact

of [rehab] scared me. So a lot of the time I was alone, and I'd just push people away, and I didn't want to be near them, I didn't want to talk to anyone. I needed time to think, basically." In connecting-separating from others and projects, participants simultaneously revealed-concealed of themselves and were enabled-limited by their choices.

Theme Four: Bewildering Uncertainties

The fourth theme of the current study, bewildering uncertainties, relates most directly to the human becoming theme of transcendence and the human becoming principle - cotranscending with the possibles is powering unique ways of originating in the process of transforming (Parse, 1981, p. 69). The human becoming theme transcendence is about moving on with a pushing-resisting force that propels one toward the possibles. While moving and changing unique options surface with new views of life and situations (Parse, 1998; Pilkington & Jonas-Simpson, 1996). Uncertainty was present in the participants view of life. Three concepts are related to the HBT principle and theme of transcendence: powering, originating and transforming.

Powering is the energizing force in the human-universe process. Amid the pushing-resisting rhythm of this force, tensions and conflicts arise with daily struggles that threaten what was, is and will be. When asked about the future, one participant replied "That's a hard question. I don't know. Basically, I'm just focusing on getting myself up, just getting one thing at a time fixed. I'm totally scared to go to rehab, like totally frightened. But then, I'm totally excited at the same time." The tension and conflict surface opportunities for choosing new ways of being with and looking at

situations while moving beyond. In the excerpt above, the participant spoke about “just focusing” as a way to be with the uncertainty of the situation.

Originating is the second concept associated with the human becoming theme transcendence. Originating is about choosing individual and unique ways to be with others, and situations, while moving onward amidst the uncertainty of the not-yet-known. The rhythm of choosing to be like and unlike others forges a personal path that creates sureness and unsureness. Participants expressed exclusive viewpoints with determination about how life would unfold, yet amongst the certainty that determination implies, uncertainty was clearly present. One participant stated,

I still see family outings, only I'll be in a wheelchair. And I see that and accept that, so far. But maybe I'm being blind. There's that fear too, because I've never experienced it. Maybe I won't be able to handle it. I don't know. I know there are things in place for me - supports. If I need them, they're there.

Even in the midst of the unknown, the participant is sure of the support available to in her future. As she continues, a unique way of being with her injury and others emerges. “I know quite a few paraplegics, young ones. And I thought, maybe we could have a group that meets once a month, just for support, maybe I could initiate that.”

Transforming is the third concept related to the human becoming theme of transcendence. Transforming is the shift in perspective as the everyday emerges in a new light. This shift occurs in the rhythmical struggle between the familiar and unfamiliar amongst the continuous change of co-creation. As the situation unfolds, participants come to, or discover a new and evolving understanding of life's experiences. One participant stated “I just discovered a couple of days ago this is the first day of my

life, really. Life as I knew it, a good part of it is gone. So it's important for me to get on with it and do the best I can with it." For participants, the unfamiliar was ever present as they considered their situation.

Parse's (1981,1990,1992, 1994, 1998, 1999) theory of human becoming provides a unitary way of viewing persons' experience of QOL. Discussion of the themes of the current study in light of the predominant themes and concepts of the HBT expands both the understanding of the participants' experiences and the human becoming theory. The theory provides insight into how persons shape the QOL they experience through the unique meaning they ascribe to situations, relationships with others, and the way in which they choose to participate in their life as it unfolds.

CHAPTER VI

Conclusions, Implications, and Reflections

This research study explored the experience of quality of life (QOL) for persons with spinal cord injury (SCI) in the acute care setting. The purposes of this qualitative investigation were: (a) to describe patients' perspectives of QOL when living with SCI in the acute care setting; and b) to enhance understanding of QOL issues for additional study; c) to specify practice approaches aimed at enhancing QOL for persons with SCI; and d) to expand the guiding framework, the human becoming theory (HBT). Guided by Parse's (1981,1990,1992, 1994, 1998, 1999) HBT, this descriptive-exploratory study explicated the perspective of quality of life for six participants between the age of 19 and 67 within 4-12 weeks after SCI.

Findings consisted of four themes that captured common essences in the participants' descriptions. Consistent with the descriptive method outlined by Parse et al. (1985), the themes were named in the researcher's language and form a unified description answering the research question: What is the QOL for persons with SCI living in acute care. A unified description provides the reader with a comprehensive description of the phenomenon as lived by the participants. The unified description is; Dwelling with enriching affiliations and resolving to prevail while considering alternative views amid bewildering uncertainties.

Findings were discussed in relation to participants' descriptions, related research literature, and Parse's theoretical principles and concepts. Findings broaden nursing's scientific knowledge base and further the insight and understanding of the experience of QOL for persons with SCI in the acute care setting in relation to meanings, relationships,

priorities, and hopes and dreams. In this chapter, conclusions emerging from this study, and implications for practice and further research are offered.

Conclusions

The findings from this study contribute unique knowledge about the experience of QOL for persons living with SCI in the acute care setting. Themes one and two, *resolving to prevail* and *considering alternative views* illustrate how participants' attitudes and approach toward life contribute to the unique meaning of QOL. Continuing on through difficult circumstances has been described by other researchers in connection with hope (Allchin-Petardi, 1999; Cody & Filler, 1999; Pilkington & Millar, 1999) and serious illness (Allchin-Petardi, 1998; Dunbar, Mueller, Medina & Wolf, 1998).

Participants' perspectives shifted as they considered their situation in light of what was important to them and the situations of others. The shift in participants' perspectives described in theme two may explain the lack of significant correlation in other studies among QOL/life satisfaction and variables including: level of injury, completeness of injury, physical function, disability, and ventilator dependency. (Bach & Tilton, 1994; Crushman & Hassett, 1992; Dunnum, 1990; Kreuter et al., 1998; Lundqvist et al., 1997; Nieves et al., 1991; Post, van Dijk et al., 1998; Siosteen et al., 1990; Whiteneck et al., 1992; Westgren & Levi, 1998). Priorities are re-evaluated in light of the person's own circumstances and others around them. The importance of physical abilities, for example, may change. Other researchers have described a similar phenomenon with other serious illnesses (Allchin-Petardi, 1998; Halldorsdottir & Hamrin, 1996; Loveys & Klaich, 1991; Mishel & MurDaugh, 1987; Pelusi, 1997; Pilkington, 1999; Steeves, 1992)

The findings illuminate how participants contributed to the creation of their QOL by choosing to view and approach life in a particular way. Participants spoke with intent about overcoming the situation and fulfilling personal potential in light of clarified values and priorities. The themes depict how participants continued onward in the face of the life altering experience of SCI and how persons shape the QOL they experience through the choices they make to view their situation in certain ways. "Attitude toward life is the most significant determinant of QOL" (Boswell et al, 1998).

The third theme, *dwelling with enriching affiliations* describes what relationships contribute to participants' experience of quality of life including comfort, gratification, support and encouragement. The descriptions contributing to the theme indicate that relationships contribute to QOL even in the absence of the person with whom the participant has the relationship with. Reflection or dwelling on, plus speaking of both the existence of the relationship and the quality of the relationship enhanced participants' QOL. The findings of the current study broaden understanding of how relationships contribute to QOL for persons living with SCI.

Finally, theme four, *bewildering uncertainties* reflects the perplexity the participants experienced as they continue on with their lives without the confidence of an established image of what their life might be like. Participants were unable to provide a description about what life might be like because they did not know. Although uncertainty had been linked to QOL for persons living with cancer (Bertero & Eriksson, 1997; Dow, Ferrell, Leigh, Ly & Gulasekaram, 1996; Ferrell, Grant, Funk, Garcia, Otis-Green & Schaffner, 1996; Halldorsdottir & Hamrin, 1996; Loveys & Klaich, 1991; Pelusi, 1997), it had not been linked to QOL for persons with SCI and

these findings provide a deeper understanding into the experience of persons with SCI in the acute care setting in addition to adding new knowledge to nursing science.

Implications of Findings

The current study has contributed to advancing nursing science through expanding understanding about the perspective of QOL for persons with SCI. This enriched understanding provides opportunities to suggest practice approaches for health professionals who work with patients with SCI and to examine the findings for questions to generate further research. In the following section, expansion of the theoretical framework, implications for professional practice, and recommendations for future research are discussed.

Expansion of the Theoretical Framework

The underlying principles of the HBT (Parse, 1981,1990,1992, 1994, 1998, 1999) guided this research project. The HBT assumes individuals structure meaning and co-create reality, co-participate in patterns of relating with others, and experience new ways of looking at the familiar in light of concerns, plans, hopes, and dreams. The theory provides a structure of basic assumptions related to human beings, health and QOL. Parse states that QOL is the “whatness... or the essence of life” (Parse, 1994, p.17). The findings of this research study illustrate the “whatness”, that is, the QOL for the participants of this study. The unitary perspective captures QOL in process (Parse, 1994). Ongoing research guided by the theory expands the theory by filling in depth and details of the “whatness” of lived experiences, similar to an artist filling in a picture with color and texture (Mitchell, 1992).

The themes, *resolving to prevail* and *considering alternative views* provide descriptions linked with the HBT theme *meaning*. Meaning is the constructing of personal reality through assigning significance to individual experiences (Parse, 1998; Pilkington & Jonas-Simpson, 1996). The themes, *resolving to prevail* and *considering alternative views* shed light on how meaning of QOL is constructed through participants' approach and view of life.

The theme *dwelling with enriching affiliations* is linked to the HBT theme *rhythmicity* and reveals the complexity of the human experiences as seemingly opposite, patterns of relating are lived all at once. These paradoxes are evident throughout the participants' descriptions of being with, and away from others. Relationships continued to unfold amid the opportunities and restrictions of the situation.

The fourth theme, *bewildering uncertainties*, enhances understanding of the HBT theme *co-transcendence* depicting moving on with a pushing-resisting force that propels one toward the possibles. While moving and changing unique options surface with new views of life and situations (Parse, 1998; Pilkington & Jonas-Simpson, 1996). Uncertainty was weaved throughout the participants' view of life and in the midst of uncertainty lies the potential for new directions.

The participants' descriptions of the "whatness" provide detail and texture to the basic assumptions of the HBT. The themes of the current study surface new understanding of the lived experience the theoretical principles encompass. This new understanding contributes to the knowledge base of the theory.

Implications for Professional Practice

For health care providers, what is not present in the findings of the current study may be as interesting as the findings themselves. Upon viewing the findings readers may ask: Weren't the participants angry? Weren't the participants grieving? Participants may have experienced these feelings, however, these descriptions did not consistently emerge in the descriptions of QOL. Readers may feel the participants (or the researcher) presented optimistic descriptions, however, the participants' descriptions included the limitations and challenges participants saw in their life. Persons with SCI continue onward in the midst of life altering events and the experience of QOL is shaped by values, priorities, relationships with others, and uncertainty.

A nurse whose practice is guided by Parse's theory does not attempt to predict or control persons' responses to illness (1981,1990,1992, 1994, 1998, 1999). The findings of this study are not to be generalized to all persons with SCI, nor are they meant to prescribe interventions to enhance QOL. The intent of this research was to increase understanding and the awareness of the experience of QOL for persons with SCI. Enhancing understanding of persons' experiences can change nurses' perceptions of what it is like to live with SCI, it can change how nurses feel about caring for patients with SCI, and it can change how nurses are in relationships with patients.

Understanding that perceptions, values and priorities shift after SCI can help staff invite patients to talk about what is important to them, and to listen intently as patients talk about seeing things and valuing things differently. In the process of talking about what is valued, perspectives shift and patients have the opportunity to see things in a different way. The shift in attitude and outlook contribute to the experience of QOL for

the person. Nurses have opportunities to honour and support the fortitude of persons as they talk about moving onward. Nurses can be there to hear the satisfaction of the person who realizes one can continue with what is important and find enjoyment in life.

Participants in the current study spoke of seeing themselves as better off than others in comparison. Mitchell (1998) suggests that by providing opportunities for patients to make comparisons among people, places, and times, a metaperspective of self in light of others may surface strengths not evident to the person before. One participant stated,

I came out with the impression that I'm not that bad, compared to some people.

And that's kind of uplifting in a way. I mean, when you know that, you know, you're going to be in a wheelchair for life, but there's still people worse, it's not that bad of a feeling, you know.

Nurse-person discussions can provide patients with an opportunity to explore different ways of approaching life and what that might be like. Nurses can ask questions to initiate discussion with the patient such as "How do you see yourself being with the changes in your life?"

Relationships with various people, including hospital staff contributed to the participants QOL. Nurses have an opportunity to contribute to person's QOL by forming genuine relationships which respect the person's uniqueness and that honors the person's experience. Relationships between nurses and persons, although not solely dependent on the time spent together, have more potential in environments where continuity of care is promoted. Evidence of how relationships with staff can enhance patient's QOL is evident in the following statement " I remember several times I'd be laying here at night,

and one of the nurses would come in and just sit with me. They'd sit and talk with you, sometimes just brush your hair back, or whatever. That just felt like family."

It goes without saying that opportunities for patients to be with people who are important to them should be promoted. Open or expanded visiting hours, and overnight arrangements are becoming more common in acute care settings. Technology provides opportunities for nurses to facilitate the connection between patients and persons important to them in other ways as well. One participant spoke of how meaningful it was for the staff to arrange for a VCR so she could watch her the videotape of her daughter's graduation, which she had missed. Telephones with head sets provide a way for quadriplegic patients to communicate by phone without requiring anyone to hold the phone for them. As technology advances many other ways of being with important people may emerge.

The findings of the current study suggest that even in the absence of important others, the invitation to speak about relationships by the nurse, can evoke feelings that enhance the person's QOL. Open questions such as "Who is important in your life?" or "What does your family mean to you?" provides an invitation to the person.

Professional care-givers reading the current study findings may be more open to hearing the experience, concerns and priorities of patient's with spinal cord injury. One participant shared her need to talk.

I wish you could talk to, well, the nurses, they're always busy. The unit nurses were a lot better about sharing. Sometimes you could have a cry, or like voice a doubt or a fear. There's no place for that here. And then, because I don't have my husband, there's no-one really to interact with. I find that hard.

The findings of this study also have implications beyond direct caregivers. All of the participants of this study had been transferred from their communities to provide specialized care through the Acute Care Spinal Cord Injury in a metropolitan tertiary hospital. This action may separate patients from the people who contribute most to their QOL. Accommodations for out of town families, special support allowances, and tax benefits for families supporting patients away from home, are three ideas to enable to support having important people near.

Although the findings of this study suggest that uncertainty is present for persons living with SCI, what that uncertainty means for each participant will be unique. If individuals talk about not knowing what the future holds, exploring with phrases such as “Tell me more about not knowing” or asking “What is it like not to know?” helps to learn what unique meaning uncertainty holds for that individual and how it impacts life. If the uncertainty or meaning is disturbing for the person, asking “What helps with the not knowing?” provides the person with an opportunity to discuss personal strategies and to perhaps see the unknown in a new light.

Finally, health professionals who have the opportunity to reflect on the findings of the study will know that the way in which professionals are with persons with SCI influences their experience of QOL. Everyday moments when care providers are with persons with SCI provides opportunities to enhance QOL, despite seemingly devastating life events. The challenge to professionals is to have the courage to engage with persons with SCI in ways that make a difference. Professionals also need to continue to do research that builds understanding of the experiences of persons living with SCI.

Recommendations For Future Research

In the process of explicating knowledge about QOL for persons living with SCI, further research questions have been generated. This fulfills a secondary purpose of this study. The research questions link to the themes and the following universal lived experiences:

What is the experience of taking life day by day?

What is the experience of suddenly seeing something in a different way?

What is the experience of viewing a situation as a challenge?

What is the experience of feeling uncertain?

This research project focused on QOL for persons with SCI within the acute care setting. In order to understand changes in QOL over time for persons with SCI, it would be helpful to follow participants longer. In addition, there is an opportunity to explore the paradox of certainty-uncertainty for persons with acute SCI and with those after several years of injury to understand both the complexities and variations among patterns and groups.

Reflections

As a novice nurse working on a neuroscience floor with persons living with SCI, I ended up talking about the weather to patients who had sustained life altering injuries as I did not know how to be helpful. Personal motivation for the current study included providing an opportunity for myself and others to learn more about the experience of QOL for persons with SCI in the hopes that others reading the study would be aware of how genuine nurse-person discussions can enhance QOL. I also wanted to deepen my knowledge and understanding of the HBT.

I have grown in my understanding of the HBT during the project. In addition, through completing this study I have become more comfortable being with persons living through difficult situations. I have had the opportunity to share the findings of the current study with Parse scholars, colleagues, and students. A student stopped me in the hall a week later to tell me about an interaction she had with a patient with SCI she was caring for, and how the study had changed how she was with the person. A colleague who had completed her Ph.D. dissertation with the HBT has stated the theme *dwelling with enriching affiliations* resonated with her and thinks about it in practice and teaching situations. The current study has been deeply rewarding on both a personal and professional level.

The current study has provided insight into how persons continue to find QOL after life altering events. It is my sincere hope that after reading the findings of this study that other nurses will resolve to risk the uncertainty of not knowing what will emerge, and invite persons with SCI to talk about what life is like for them, who is important to them, and what they hope the future will hold.

References

- Allchin-Pertardi, L. (1998). Weathering the storm: Persevering through a difficult time. Nursing Science Quarterly, 11, 172-177.
- Allchin-Petardi, L. (1999). Hope for American women with children. In R.R. Parse (Ed), Hope: An international Human Becoming Perspective (pp. 273-288). Boston, MA: Jones and Bartlett.
- Aaronson, N. K. (1991). Methodological issues in assessing the quality of life of cancer patients. Cancer, 67, 844-850.
- Anke, W.A.G., Stenehjem, A. E. & Stanghell, J. K. (1995). Pain and quality of life within 2 years of spinal cord injury. Paraplegia, 33, 555-559.
- Ayres, L. & Poirer, S. (1996). Virtual text and the growth of meaning in qualitative analysis. Research in Nursing & Health, 19, 163-169.
- Bach, C. A. & McDaniel, R. W. (1993). Quality of life in quadriplegic adults: A focus group study. Rehabilitation Nursing, 18, 364-367.
- Bach, J. R. & Tilton, M. C. (1994). Life satisfaction and well-being measures in ventilator assisted individuals with traumatic tetraplegia. Archives of Physical and Medical Rehabilitation, 75, 626-632.
- Bertero, C & Eriksson, B.E. (1997). Explaining different profiles in quality of life experiences in acute and chronic leukemia. Cancer Nursing, 20, 100-104.
- Bournes, D.A. (1997). Quality of life: Exploring the perspective of patients with congestive heart failure. Unpublished masters thesis, University of Toronto.
- Boswell, B.B. , Dawson, M. & Heining, E. (1998). Quality of life defined by adults with spinal cord injuries. Journal of Rehabilitation, 64, 27-32.

Brown, I., Renwick, R., & Nagler, M. (1996). The Centrality of Quality of Life in Health Promotion and Rehabilitation. In R. Renwick, I. Brown, & M. Nagler, (Eds.), Quality of life in health promotion and rehabilitation. Conceptual approaches, issues and applications (pp. 3-13). Thousand Oaks, Ca: Sage Productions.

Burns, N. (1989). Standards for qualitative research. Nursing Science Quarterly, 2, 44-52.

Burns, N. & Grove, G. (1993). The Practice of Nursing Research: Conduct, critique & utilization. Philadelphia: W.B. Saunders Co.

Butler, R. N. (1992). Quality of life: Can it be an endpoint? How can it be measured? American Journal of Clinical Nutrition, 55, 126S-1270S.

Calman, K. C. (1984). Quality of life in cancer patients - an hypothesis. Journal of Medical Ethics. 10, 124-127.

Campbell, A., Converse, P.E. & Rodgers, W.L. (1976) The quality of American life: Perceptions, evaluations and satisfactions. New York: Russel Sage Foundation.

Canadian Paraplegia Association. (1993). 1992-1993 Annual Report. Toronto: Canadian Paraplegia Association.

Carlson, C. E. (1979). Conceptual style and life satisfaction following spinal cord injury. Archives of Physiological and Medical Rehabilitation, 60, 346-352.

Carson, M.G. & Mitchell, G.J. (1998). The experience of living with persistent pain. Journal of Advanced Nursing, 28, 1242-1248.

Clayton, K. S. & Chubon, R. A. (1994). Factors associated with the quality of life of long-term spinal cord injured persons. Archives of Physical and Medical Rehabilitation, 75, 633-638.

Close, H. & Proctor, S. (1999). Coping strategies used by hospitalized stroke patients: implications for continuity and management of care, Journal of Advanced Nursing, 29, 138-144.

Cody, W. K. & Filler, J. E. (1999) The lived experience of hope for women residing in a shelter. In R.R. Parse (Ed), Hope: An international Human Becoming Perspective (pp.211-226). Boston, MA: Jones and Bartlett.

Crewe, N. M. & Krause, J. S. (1988). Marital relationships and spinal cord injury. Archives of Physical Medicine and Rehabilitation, 69, 435-438.

Crothers, J.E. & Dolecki, P.R. (1989). Human science: Inquiry into the person. Person-Centered Review, 4, 446-464.

Crushman, L. A. & Hassett, J. (1992). Spinal cord injury: 10 and 15 year after. Paraplegia, 30, 690-696.

DeGroot, H. (1988). Scientific inquiry in nursing in a model for a new age. Advances in Nursing Science, 10(3), 1-21.

Denzin & Lincoln, 1994; Introduction; Entering the Field of Qualitative Research. In N.K. Denzin & S.L. Lincoln, (Eds.) Handbook of Qualitative Research (pp. 1-17) Thousand Oaks, CA: Sage.

Dijkers, M. (1996). Quality of life after spinal cord injury. American Rehabilitation, 22(3), 18-24.

Dijkers, M. (1997). Quality of life after spinal injury: A meta analysis of the effects of disablement components. Spinal Cord, 35, 829-840.

DeVivo, M. J. & Richards, J. S. (1992). Community reintegration and quality of life following spinal cord injury. Paraplegia, 30, 108-112.

- Dow, K. H., Ferrel, B.R. Leigh, S., Ly, J. & Gulasekaram (1996). An evaluation of the quality of life among long-term survivors of breast cancer. Breast Cancer Research and Treatment, 39, 261-273.
- Draper, P. (1991). Quality of life as quality of being: an alternative to the subject-object dichotomy. Journal of Advanced Nursing, 17, 965-970.
- Dudley-Brown, S. (1996). Living with Ulcerative Colitis. Gastroenterology Nursing, 19, 60-64.
- Dunbar, H. T. , Mueller, C. W. Medina, C. & Wolf, T. (1998) Psychological and spiritual growth in women living with HIV. Social Work, 43, 145-154.
- Dunnum, L. (1990). Life satisfaction and spinal cord injury: The patient perspective. Journal of Neuroscience Nursing, 22, 43-47.
- Elliot, R., Fischer, C.T. & Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. British Journal of Clinical Psychology, 38, 215-229.
- Ferrans, C. E. (1990). Quality of Life: Conceptual Issues. Seminars in Oncology Nursing, 6, 248-254.
- Ferrel, B.R., Grant, M., Funk, B., Garcia, N., Otis-Green, S., Schaffner, M.L.J., (1996). Quality of Life in Breast Cancer. Cancer Practice, 4, 331-340.
- Finfgeld, D. L. (1995). Becoming and being courageous in the chronically ill elderly. Issues in Mental Health Nursing. 16, 1-11.
- Fisher, A. M. & Mitchell, G.J. (1998). Patient's views of quality of life: Transforming the knowledge base of nursing. Clinical Nurse Specialist, 12, 99-105.
- Fuhrer, M. J., Rintala, D. H., Hart, K. A., Clearman, R. & Young M. E. (1992). Relationship of life satisfaction to impairment, disability, and handicap among persons

with spinal cord injury living in the community. Archives of Physical Medicine and Rehabilitation, 73, 552-557.

Gerhart, K. A., Berstrom, E., Charlifue, S. W., Mentor, R. R. & Whiteneck, G. G. (1993). Long-term spinal cord injury: Functional changes over time. Archives of Physical Medicine and Rehabilitation, 74, 1030-1034.

Gerhart, K. A., Koziol-McLain, J., Lowenstein, S. R. & Whiteneck, G. G. (1994). Quality of life following spinal cord injury: knowledge and attitudes of emergency providers. Annals of Emergency Medicine, 23, 807-812.

Gill, T. M. & Feinstein, A. R. (1994). A critical appraisal of the quality of quality-of-life measurements. Journal of the American Medical Association, 272, 619-625.

Giorgi, A. (1985). Sketch of psychological phenomenological method. In A. Giorgi (Ed.), Phenomenology and psychological research (pp. 8-22). Pittsburg: Duquesne University Press.

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

Haldenmann, V., (1993). Qualitative methods: Why? Canadian Journal of Aging, 12, 117-138.

Halldorsdottir, S. & Hamrin, E. (1996). Experiencing existential changes: the lived experience of having cancer. Cancer Nursing, 19, 29-36.

Hammell, K. R. W. (1992). Psychological and sociological theories concerning adjustment to traumatic spinal cord injury: The implications for rehabilitation. Paraplegia, 30, 317-326.

Hickey, J. V. (1986). Vertebral and spinal cord trauma. In J. V. Hickey, Neurological and Neurosurgical Nursing (2nd ed, pp. 378-423). Philadelphia: J.B. Lippincott.

Holmes, C.A. (1989). Health care and the quality of life: A review. Journal of Advanced Nursing 14, 833-839.

Hughes, B. (1990). Quality of Life. In S. M. Peace (Ed.), Researching social gerontology - concepts, methods and issues (pp. 46-58). Newbury Park, CA: Sage

Hughes, K.K. (1993). Psychosocial and functional status of breast cancer patients: The influence of diagnosis and treatment choice. Cancer Nursing, 16, 222-229.

Janesick, V.J. (1994). The dance of qualitative research design: Metaphor, methodolatry, and meaning. In N.K. Denzin & S.L. Lincoln, (Eds.) Handbook of Qualitative Research (pp. 209-219) Thousand Oaks, CA: Sage.

Jennings, B.M. & Staggers, N. (1994). A critical analysis of hardiness. Nursing Research, 43, 275-281.

Kannisto, M., Merikanto, J., Alaranta, H., Hokkanen, H. & Sintonen, H. (1998). Comparison of health-related quality of life in three subgroups of spinal cord patients. Spinal Cord, 36, 193-199.

Kannisto, M. & Sintonen, H. (1997). Later health-related quality of life in adults for have sustained spinal cord injury in childhood. Spinal Cord, 35, 747-751.

Kobasa, S.C. (1979a). Personality and resistance to illness. American Journal of Community Psychology, 7, 413-423.

Kobasa, S.C. (1979b). Stressful life events, personality, and health: An inquiry into hardiness. Journal of Personality and Social Psychology, 37, 1-11.

Kobasa, S.C., Maddi, S.R. & Courington, S. (1981). Personality and constitution as mediators in stress-illness relationship. Journal of Health & Social Behavior, 22, 368-378.

Kolodny, V. (1996). Quality of life: Advancing practice through research. Unpublished manuscript, Sunnybrook Health Science Centre, Toronto, Ontario, Canada.

Krause, J.S. (1997). Adjustment after spinal cord injury: A 9-year Longitudinal Study. Archives of Physical Medicine & Rehabilitation, 78, 651-657.

Krause, J. S. & Kjorsvig, S. (1992). Mortality after spinal cord injury: a four-year prospective study. Archives of Physical and Medical Rehabilitation, 73, 558-563.

Krause, J.S., Sternberg, M., Lottes, S. & Maides, J. (1997). Mortality after spinal cord injury: An 11-year prospective study. Archives of Physical Medicine & Rehabilitation, 78, 815-821.

Kreuter, M., Sullivan, M., Dahllof, A.G. & Siosteen, A. (1998). Partner relationships, functioning, mood and global quality of life in persons with spinal cord injury and traumatic brain injury. Spinal Cord, 36, 252-261.

Lambert, C.E. & Lambert, V.A. (1999). Psychological hardiness: State of the science. Holistic Nursing Practitioner, 13, 11-19.

Leininger, M. M. (1985). Ethnography and ethnonursing: Models and modes of qualitative data analysis. In M.M. Leininger (Ed.) Qualitative Research Methods in Nursing (pp. 33-73). Philadelphia: W.B. Saunders.

Loew, F. & Rapin, C. H. (1994). The paradoxes of quality of life and its phenomenological approach. Journal of Palliative Care, 10, 37-41.

Lok, P. (1996). Stressors, coping mechanisms and quality of life among dialysis patients in Australia. Journal of Advanced Nursing, 23, 873-881.

Loveys, B.J. & Klaich K. (1991) Breast Cancer Demands of illness. Oncology Nursing Forum, 18, 75-79.

Low, J. (1996). The concept of hardiness: a brief but critical commentary. Journal of Advanced Nursing, 24, 588-590.

Lundqvist, C. Siosteen, A., Blomstrand, C., Lind, B. & Sullivan, M. (1991). Spinal cord injuries; Clinical, functional, and emotional status. Spine, 16(1), 78-83.

Lundqvist, C., Siosteen, A., Blomstand, C., Lind, B. & Sullivan, M. (1997). Spinal cord injuries: A shortened measure of function and mood. Spinal Cord, 35, 17-21.

Mast, M.E. (1995). Adult uncertainty in illness: A critical review of research. Scholarly Inquiry for Nursing Practice: An International Journal, 9, 3-23.

Marshall, C. & Rossman, G.E. (1989). Designing qualitative research. Newbury Park: Sage.

McDowell, I. & Nevell, C. (Eds.). (1987). Quality of life and life satisfaction. In McDowell, I. & Nevell, C. (Eds.) Measuring health: A guide to rating scales and questionnaires. New York: Oxford Press.

McKenna, E. (1994). The Experience of a Spinal Cord Injured Person in the Acute Care Setting. Unpublished masters thesis, University of Toronto.

Miller, C. M. (1997). The lived experience of relapsing multiple sclerosis: A phenomenological study. Journal of Neuroscience Nursing, 29, 294-304.

Mishel, M. (1990). Reconceptualization of the uncertainty in illness theory. Image: Journal of Nursing Scholarship, 22, 256-262.

Mishel, M. H. & MurDaugh, C. L. (1987) Family Adjustment to heart transplantation: Redesigning the dream. Nursing Research, 36, 332-337.

Mitchell, G.J. (1992). Exploring the paradoxical experience of restriction-freedom in later life: Parse's theory-guided research. Unpublished dissertation, University of South Carolina.

Mitchell, G. J. (1993) Living paradoxes in Parse's theory. Nursing Science Quarterly, 6, 44-51.

Mitchell, G.J. (1994) Discipline-specific inquiry: The hermeneutics of theory-guided nursing research. Outlook, 42, 224-228.

Mitchell, G.J. (1998). Living the diabetes: How understanding expands. Canadian Journal of Diabetes, 22, 30-37.

Mitchell, G.J., Carson, G., Fisher, A., Kolodny V., & Vander Laan, R. (1994). Quality of life: Exploring the client's perspective. Unpublished manuscript, Sunnybrook Health Science Centre, Toronto, Ontario, Canada.

Mitchell, G.J. & Lawston, C. (2000), Living with the consequences of personal choices for person with diabetes: Implications for educators and practitioners. Canadian Journal of Diabetic Care, 24, 23-20.

Morse, J. (1992). If you believe in theories, Qualitative Health Research 2, 259-261.

Morse, J. (1994). Designing Funded Qualitative Research. In N.K. Denzin & S.L. Lincoln, (Eds.) Handbook of Qualitative Research (pp. 215-241) Thousand Oaks, CA: Sage.

National Spinal Cord Injury Statistical Centre. (1994) Fact Sheet # 2. Birmingham, AL: National spinal Cord Injury Statistical Center.

Nieves, C. C., Charter, R. A. & Aspinall, M. J. (1991). Relationship between effective coping and perceived quality of life in spinal cord injured patients.

Rehabilitation Nursing, 16(3), 129-132.

Noreau, L. & Shephard, R. J. (1995). Spinal cord injury, exercise and quality of life. Sports Medicine 20, 226-250.

Nyman, C. S. & Lutzen, K. (1999). Caring Needs of Patients with rheumatoid arthritis. Nursing Science Quarterly, 12, 164-169.

Omery, A. (1983). Phenomenology: A method for nursing research. Advances in Nursing Science, 5, 49-63.

Padilla, G.V. & Grant, M. (1985). Quality of life as a cancer nursing outcome variable. Advances in Nursing Science, 8, 45-60.

Parmenter, T. R. (1996). The use of quality of life as a construct for social and health policy development. In Renwick, R., Brown, I. & Nagler, M. (Eds.) Quality of life in health promotion and rehabilitation. Conceptual approaches, issues and applications. (pp. 89-103). Thousand Oaks, Ca: Sage Publications.

Parse, R. R. (1981). Man-Living-Health: A theory of nursing. New York: Wiley Medical Publication.

Parse, R. R. (1990). Health: A personal commitment. Nursing Science Quarterly, 3(2), 136-140.

Parse, R. R. (1992). Human becoming: Parse's theory of nursing. Nursing Science Quarterly, 5, 35-42.

Parse, R. R. (1994). Quality of life: Sciencing and living the art of human becoming. Nursing Science Quarterly, 7, 16-21.

Parse, R.R. (1998). The Human becoming school of thought : A perspective for nurses and other health professionals. Thousand Oaks, Ca: Sage Productions

Parse, R.R. (1999). Hope : A lived experience of human becoming. In R.R. Parse (Ed.) Hope: An International Human Becoming Perspective. (pp. 1-8). Sudbury, MA: Jones & Bartlett.

Parse, R. R., Coyne, A. B., Smith, M. J. (1985). Nursing research: Qualitative methods. Bowie, MD: Brady.

Pelusi, J. (1997) The lived experience of surviving breast cancer. Oncology Nursing Forum. 24, 1343-1353

Pentland, W., McColl, M.A. & Rosenthal, C. (1995). The effect of aging and disability on long term health outcomes following spinal cord injury. Paraplegia, 33, 367-373

Pilkington, F.B. (1997). Persisting while wanting to change: Research guided by Parse's theory. Unpublished dissertation, Loyola University Chicago.

Pilkington, F. B. (1999). A qualitative study of life after stroke. Journal of Neuroscience Nursing. 31, 336-347.

Pilkington, F.B. & Jonas-Simpson, C. (1996). The human becoming theory. A manual for the teaching-learning process. International Consortium of Parses Scholars.

Pilkington, F. B. & Millar, B. (1999) The lived experience of hope with persons from Wales, UK. In R.R. Parse (Ed), Hope: An International Human Becoming Perspective (pp. 163-190). Boston, MA: Jones and Bartlett.

Pollock, S.E. & Duffy, M.E. (1990). The health-related hardiness scale: Development and psychometric analysis. Nursing Research, 39, 218-222.

Post, M.W.M., de Witte, L.P., Floris, W.A., van Asbeck, F.W.A., van Dijk, A.J. & Schrijvers, A.J.P. (1998). Predictors of health status and life satisfaction in spinal cord injury. Archives of Physical Medicine & Rehabilitation. 79, 395-401.

Post, M.W.M., van Dijk, A.J., van Asbeck, F.W.A. & Schrijver, A.J.P. (1998). Life satisfaction of persons with spinal cord injury compared to a population group. Scandinavian Journal of Rehabilitation Medicine, 30, 23-30.

Prince, J. M., Manley, M. S., & Whiteneck, G. G. (1995) Self-managed versus agency-provided personal assistance care for individuals with high level tetraplegia. Archives of Physical and Medical Rehabilitation, 76, 919-923.

Ray, M.A. (1985). A Philosophical method to study nursing phenomena. In M.M. Leininger (Ed.) Qualitative Research Methods in Nursing (pp. 81-92).

Philadelphia: W.B. Saunders

Sandelowski, M. (1995a). Sample size in qualitative research. Research in Nursing & Health, 18, 179-182.

Sandelowski, M. (1995b). Qualitative analysis: What it is and how to begin. Research in Nursing & Health, 18, 371-375.

Sandelowski, M. (1998). The call to experts in qualitative research. Research in Nursing & Health, 21, 467-471.

Sandelowshi, M. (2000). Whatever Happened to Qualitative Description. Research in Nursing & Health, 23, 334-340.

Siosteen, A., Lundqvist, C., Blomstrand, C., Sullivan, L., & Sullivan, M. (1990) The quality of life of three functional spinal cord injury subgroups in a Swedish community. Paraplegia, 28, 476-488.

Steeves, R.H. (1992). Patients who have undergone bone marrow transplantation: Their quest for meaning. Oncology Nursing Forum, 19, 899-905.

Stensman, R. (1994). Adjustment to traumatic spinal cord injury. A longitudinal study of self-reported quality of life. Paraplegia, 32, 416-422.

Sutcliffe & Holmes, (1991). Quality of life verification and use of a self assessment scale in 2 populations. Journal of Advanced Nursing, 16, 490-498.

Toikkanen, U. & Muurinen, E. (1999). Toivo: Hope for Persons in Finland. In R.R. Parse (Ed), Hope: An International Human Becoming Perspective (pp.79-96). Boston, MA: Jones and Bartlett.

Wang, H. C. (1999). He-Bung: Hope for persons living with leprosy in Taiwan. In R.R. Parse (Ed), Hope: An International Human Becoming Perspective (pp.144-162). Boston, MA: Jones and Bartlett.

Warren, L., Wrigley, M., Yoels, W.C. & Fine, P.R. (1996). Factors associated with life satisfaction among a sample of persons with neurotrauma. Journal of Rehabilitation Research and Development, 33, 404-408.

Westgren, N. & Levi, R. (1998). Quality of life and traumatic spinal cord injury. Archives of Physical Medicine & Rehabilitation, 79, 1433-1439.

Whedon, M. Stearns, D. & Mills, L.E. (1995). Quality of life of long-term adult survivors of autologous bone marrow transplantation. Oncology Nursing Forum, 22, 1527-1537.

White, F. J., Rintala, D. H., Hart, K. A. & Fuhrer, M. J. (1993). Sexual activities, concerns and interests of women with spinal cord injury living in the community. American Journal of Physical and Medical Rehabilitation. 72, 372-378.

White, F. J., Rintala, D. H., Hart, K. A., Young, M. E. & Fuhrer, M. J. (1993). Sexual activities, concerns and interests of men with spinal cord injury. American Journal of Physical and Medical Rehabilitation, 71, 372-378.

Whiteneck, G. G., Charlifue, S. W., Frankel, H. L., Fraser, M. H., Gardner, B. P., Gerhart, K. A., Krishnan, K. R., Menter, R. R., Nuseibeh, I. & Short, D. J. (1992). Mortality, morbidity, and psychosocial outcomes of persons spinal cord injured more than 20 years ago. Paraplegia, 30, 617-30.

Willman, A. (1999) Hopp: The lived Experience for Swedish Elders. In R.R. Parse (Ed), Hope: An International Human Becoming Perspective (pp.129-142). Boston, MA: Jones and Bartlett.

Wineman, N.M., Durand, E.J., & Steiner, R.P. (1994). A comparative analysis of coping behavior in persons with multiple sclerosis or a spinal cord injury. Research in Nursing & Health, 17, 185-194.

Yoshida, K. (1997) Uncertainty in the lives of people with spinal cord injury and rheumatoid arthritis. Canadian Journal of Rehabilitation, 10, 5-14.

APPENDIX A

Literature Review

Table A1: Summary of Study Characteristics and Findings Related to Quality of Life

Author & year of publication	Purpose of Study	Study Design	Sample Size	Tool & Inventor	Findings related to Quality of life for Person's with Spinal Cord Injury	Limitations related to Quality of Life for Person's with Spinal Cord Injury
		Sample Selection	Time since injury			
Carlson (1979)	To explore the relationship between conceptual style and life satisfaction following a physical loss	correlational nonrandom sample selection	N=41 > 18 months since injury	<ul style="list-style-type: none"> • 15 item scale Crabbe & Scott (as cited in Carlson, 1979) 	<ul style="list-style-type: none"> • significant correlation (+) between life satisfaction and the belief system comprised of characteristics of complexity, criticalness, candor, openness, internal control orientation 	<ul style="list-style-type: none"> • participants men only • tool not designed for use with SCI population • no global rating of overall satisfaction • no opportunity to identify what was important to life satisfaction or to supplement items offered by investigators
Crewe & Krause (1988)	To determine whether patterns favoring post-injury marriage would be	descriptive random sample selection	N-122 mean 8 years since injury	<ul style="list-style-type: none"> • Modified Life Satisfaction Questionnaire (investigators) • 5 point likert satisfaction scale for 11 	<ul style="list-style-type: none"> • average life satisfaction reflected positive feelings about life • persons married post-injury reported greater satisfaction in the following areas: sex lives, living arrangements, social 	<ul style="list-style-type: none"> • no global rating of overall satisfaction • no opportunity to identify what was important to life satisfaction or to supplement items

Crewe & Krause con't	confirmed in a study statistically controlling age differences				items (investigators)	lives, health, emotional adjustment and feeling of control	offered by investigators <ul style="list-style-type: none"> focus of study related to timing of marriage/injury and satisfaction
Dunnum (1990)	To investigate the correlation between life satisfaction and physical function	correlational random sample selection	N=31 > 6 months after rehab	<ul style="list-style-type: none"> Life Satisfaction in Elderly Tool (LSES) Salamon & Conte (as cited in Dunnum, 1990) 	<ul style="list-style-type: none"> subjects reported predominantly positive feelings of life satisfaction 	<ul style="list-style-type: none"> tool created for elderly no global rating of overall satisfaction no opportunity to identify what was important to life satisfaction or to supplement items offered by investigators focus on physical function 	
Siosteen, Lundqvist, Blomstrand, Sullivan & Sullivan (1990)	To define the self-reported physical & psychosocial wellbeing, socio-demographic factors, & environment related to degrees of participation	descriptive correlational nonrandom sample selection	N=56 median 2.8 years since injury	<ul style="list-style-type: none"> QOL analogue scale (McDowell & Newell, 1987) 	<ul style="list-style-type: none"> no correlation between QOL and severity of disability QOL correlated significantly (+) with the following: social activity, ability to drive/ or transfer independently to car, level of gainful employment and level of education 	<ul style="list-style-type: none"> direction of association cannot be determined no opportunity to identify what was important to QOL or to supplement items offered by investigators 	

Siosteen et al cont'd	in available activities					
Lundvist, Siosteen, Blomstrand, Lind & Sullivan (1991)	To define the QOL of SCI patients: physical, psychological wellbeing, social functioning & wellbeing	correlational nonrandom sample selection	N=98 median 2.3 years since injury	<ul style="list-style-type: none"> analogue scale (investigators) 	<ul style="list-style-type: none"> decreased perception of QOL correlated significantly (-) with pain severe enough to impair activities of daily living regular income, youth, and time elapsed after injury correlated significantly (+) with QOL scores medical complications correlated significantly (-) with QOL no correlation between QOL gender, marital status, housing and education 	<ul style="list-style-type: none"> phenomenon (QOL) not defined statement associated with scale not reported no opportunity to identify what was important to QOL or to supplement items offered by investigators
Nieves, Charter & Aspinall (1991)	To describe the impact of physical, psychological, & social factors on the perception of QOL of SCI patients	correlational nonrandom sample selection	N=40 > 2 years since injury	<ul style="list-style-type: none"> QOL Index (Padilla & Grant, 1985) 	<ul style="list-style-type: none"> no significant differences between quadriplegics and paraplegics in QOL rating persons with higher level of coping reported higher QOL scores higher level of coping correlated significantly (+) with years since injury 	<ul style="list-style-type: none"> tool developed for use with oncology populations no opportunity to identify what was important to QOL or to supplement items offered by investigators
Bach McDaniel (1992)	To provide additional information about the	descriptive exploratory random	N=14 > 2 years, mean = 6	<ul style="list-style-type: none"> not applicable 	<ul style="list-style-type: none"> categories identified include: job & productivity, finances, health, inner strength/survival, level of activity, relationships 	<ul style="list-style-type: none"> small sample size questions framing discussion not reported

Bach McDaniel cont'd	components of QOL for quadriplegic individuals	sample selection	years since injury		<ul style="list-style-type: none"> two categories identified which are different from general populations were dependence/independence & assertiveness 	<ul style="list-style-type: none"> focus group format may influence participant responses
Crushman & Hassett (1992)	To study the current living situation & subjective QOL reported by those persons with SCI who had completed their course of inpatient rehabilitation 10 & 15 years previously	correlational nonrandom sample selection	N=43 > 10 years since injury	<ul style="list-style-type: none"> 5 point scale comparing QOL to peers (investigators) 	<ul style="list-style-type: none"> no significant correlation between QOL and level or completeness of injury no significant correlation between QOL and employment, changes in daily functioning, exercise, recreational activity, or time since injury living in a preferred life situation correlated significantly (+) with QOL majority of respondents rated own life as comparable or better than age same non-injured peers 	<ul style="list-style-type: none"> participants to rated their QOL relative to that of same age peers no opportunity to identify what was important to QOL or to supplement items offered by investigators
Fuhrer, Rintala, Hart, Clearman & Young (1992)	To assess the level and the correlates of life satisfaction for persons with SCI living in the community	correlational random sample selection	N=140 > 9 years since injury	<ul style="list-style-type: none"> Life Satisfaction Index-A (LSI-A) Neugarten (as cited in Fuhrer, Rintala, Hart, Clearman & Young, 1992) 	<ul style="list-style-type: none"> no significant correlation between satisfaction and impairment or disability life satisfaction correlated significantly (+) the following: with perceived control, amount of social support, self assessed health, social integration, occupation, mobility 	<ul style="list-style-type: none"> no global rating of overall satisfaction no opportunity to identify what was important to life satisfaction or to supplement items offered by investigators

Fuhrer Cont'd					<ul style="list-style-type: none"> • highest satisfaction was with family relationships, spiritual life & daily living tasks • lowest satisfaction related to money matters, sex life and employment 	
Krause & Kjorsing (1992)	To use a prospective data base to identify predictors of survival	descriptive nonrandom sample selection	N=347 > 2 years since injury	<ul style="list-style-type: none"> • Revised Life Situation including 5 life satisfaction items (investigators) 	<ul style="list-style-type: none"> • survivors had reported more satisfaction with the following: recreational opportunities, life opportunities, emotional adjustment, control over life, living arrangements, sexual activity • survivors greater self reported adjustment and fewer problems 	<ul style="list-style-type: none"> • QOL is not defined, inferred from results • no global rating of overall satisfaction • no opportunity to identify what was important to life satisfaction or to supplement items offered by investigators
Whiteneck, et al (1992)	To evaluate the lifetime health & functional status of persons spinal cord injured more than 20 years ago	descriptive nonrandom sample selection	N=634 > 20 years since injury	<ul style="list-style-type: none"> • QOL 5 point scale (investigators) • Individual Needs Questionnaire Flanagan (as cited in Whiteneck, et al., 1992) • Life Satisfaction Index 	<ul style="list-style-type: none"> • QOL and satisfaction not correlated with level of injury • needs ranked differently from general population; expressing selves, reading, music & entertainment rated substantially higher • helping others, learning, socializing, and participating in active recreation rated somewhat higher than general population • material comforts, having children, and work rated as 	<ul style="list-style-type: none"> • no opportunity to supplement items offered by investigators which impact QOL

Whiteneck,
et al
cont'd

(LSI)Wood
(as cited in
Whiteneck,et
al., 1992)

- somewhat less important than
general population
- QOL improved with time since
injury in younger group only,
demonstrating the largest
improvement in QOL with
individuals with least aging
effect
 - under 50 reported better life
satisfaction

White,
Rintala,
Hart, Young
& Fuhrer
(1993)

To address a
number of
questions
regarding the
behavioral
and
attitudinal
aspects of
sexuality of
men with SCI

descriptive
random
sample
selection

N=79
mean 8.8
years
since
injury

- 4 point
satisfaction
scale
(investigators)

- health, family relationships,
well being & money rated as
most important

- no global rating of
overall satisfaction
- no opportunity to
supplement items
offered by
investigators
important to life
satisfaction
- focus on sexuality

White,
Rintala,
Hart,
Young &
Fuhrer
(1993)

To assess the
sexual
activities,
concerns &
interests of
women with
SCI living in
the
community

descriptive
random
sample
selection

N=40
mean 11.2
years
since
injury

- 4 point
satisfaction
scale
(investigators)

- general health, tasks of daily
living & family relationships
rated as most important

- no global rating of
overall satisfaction
- no opportunity to
supplement items
offered by
investigators
important to life
satisfaction
- focus on sexuality

Gerhart & Berstrom (1993)	To examine the extent to which aging-related declines occur in persons with SCI & the impact on their QOL	descriptive nonrandom sample selection	N=279 > 20 years since injury	<ul style="list-style-type: none"> analogue scale (0-4) (investigators) 	<ul style="list-style-type: none"> the group not requiring more assistance rated QOL higher than group that reported increased need for assistance with age the group requiring more assistance at the time of study retrospectively rated the QOL they experienced 20 years ago as higher compared to the group who needed no extra assistance at the time of the study 	<ul style="list-style-type: none"> phenomenon (QOL) not defined statement associated with scale not reported no opportunity to identify what was important to QOL or to supplement items offered by investigators focus on aging
Stensman (1994)	To examine the adjustment of persons with complete, irreversible traumatic SCI during a period of 5 years after the injury and their self-reported QOL	longitudinal prospective nonrandom sample selection	N=17 > .5 years since injury	<ul style="list-style-type: none"> QOL analogue scale (1-10) (investigator) 	<ul style="list-style-type: none"> four patterns of adjustment utilizing QOL & coping were identified the importance of good relationships with relatives and friends was frequently mentioned in semi-structured interviews factors identified as improving QOL were individualized at three years post-injury 	<ul style="list-style-type: none"> focus of study on adjustment and coping
Clayton & Chubon (1994)	To identify issues associated with QOL	descriptive correlational nonrandom sample	N=100 > 2 years since injury	<ul style="list-style-type: none"> Life Situation Survey Chubon (as cited in Clayton & 	<ul style="list-style-type: none"> mean quadriplegic score significantly lower (86 vs. 96) than paraplegics social support items correlated significantly (+) with QOL 	<ul style="list-style-type: none"> phenomenon (QOL) not defined no opportunity to identify what was important to QOL or

Clayton & Chubon Cont'd		selection		Chubon, 1994)	<ul style="list-style-type: none"> • income had a significant but limited relationship to QOL • participants indicating student status had significantly higher QOL than those indicating employed/unemployed status 	<p>supplement items offered by investigators.</p> <ul style="list-style-type: none"> • no global rating of overall QOL.
Bach & Tilton (1994)	To evaluate life satisfaction & well-being in individuals with traumatic tetraplegia at least 2 years post injury & determine association between a number of variables	descriptive correlational nonrandom sample selection	N=360 > 2 years since injury	<ul style="list-style-type: none"> • Scale of Life Domain Satisfaction Campbell, Converse & Rodgers (as cited in Bach & Tilton, 1994) 	<ul style="list-style-type: none"> • life satisfaction rating not significantly different between ventilator dependent & non-ventilator dependent participants • social life the strongest correlation with overall life satisfaction, followed by family life • health workers in the control group significantly underestimated satisfaction • no association between age and life satisfaction 	<ul style="list-style-type: none"> • no opportunity to identify what was important to life satisfaction or to supplement items offered by investigators • no global rating of overall satisfaction • focus on ventilation status
Anke Stenehjew & Stanghell (1995)	To study the prevalence & classification of pain with SCI, the influence of pain on QOL, plus predictors for the development	Descriptive correlational random sample selection	N=46 median 32 weeks since injury	<ul style="list-style-type: none"> • General Health Questionnaire Malt, 1989 (as cited in Stenehjew & Stanghell, 1995) 	<ul style="list-style-type: none"> • significant correlation (-) between participant with pain and QOL. 	<ul style="list-style-type: none"> • no definition of QOL, QOL inferred from results of questionnaire. • no opportunity to identify what was important to QOL or to supplement items offered by investigators

Anke Stenehjew & Stanghell Cont'd Pentland, McColl & Rosenthal (1995)

of pain

To discover the independent & combined effects of age & duration of SCI on selected long term health outcomes in men with SCI

correlational

nonrandom sample selection

N=83

> 5 years since injury

- 12 item satisfaction tool Michalos (as cited in Pentland, McColl & Rosenthal, 1995)

- age significantly correlated (+) with life satisfaction

- no global rating of overall QOL
- focus on pain

- tool has not been validated with SCI population
- no opportunity to identify what was important to life satisfaction or to supplement items offered by investigators

- no global rating of overall satisfaction
- male participants
- focus on aging & time since injury

- QOL is not defined, but inferred from results on satisfaction

- tool developed for elderly

- no global rating of overall satisfaction

- no opportunity to identify what was important to life satisfaction or to supplement items offered by

Prince, Manley & Whiteneck (1995)

To determine whether a population with physical disability, had a better perceived QOL, health status, & lower cost depending on whether they used agencies vs. hired, trained, &

Quasi-experimental

non-random sample selection

N=36

> 1 year since injury

- LSI-A Neugarten as cited in Prince, Manley & Whitehead, 1995)

- self-managed group had significantly better health outcomes, fewer hospitalizations, diminished preventable complications and greater satisfaction
- - no difference in LSI score between groups

Prince,
Manley &
Whiteneck
Cont'd

trained, &
reimbursed
their
caregivers,
independent-
ly

investigators

Warren,
Wrigley,
Yoels &
Fine (1996)

To examine
the
relationship
between
rehabilitation
and life
satisfaction
in SCI and
traumatic
brain injured
population

longitudinal
nonrandom
sample
selection

N = 38
> 1 year
since
injury

- Life Satisfaction Index-A Neugarten, 1961 (as cited in Warren, et al., 1996)

- three variables significantly correlated with higher life satisfaction for SCI 1) closeness to family, 2) level of family activities, and 3) blaming self for injury (participants accepting blame for injury reported higher satisfaction than those who did not)

- no global rating of overall satisfaction
- no opportunity to identify what was important to life satisfaction or to supplement items offered by investigators

- Authors conclude life satisfaction should be a subjective, not objective measurement

Dijkers
(1997)

To describe quantitatively the relationship of subjective QOL with three aspects of disablement, impairment, disability & handicap

meta-
Analysis

29 publi-
cations

19
samples

Not-applicable

Conclusions:

- degree of impairment by itself has a very minor effect on QOL
- seven studies reported association between disability & QOL with the average correlation significant
- the average person with SCI experiences a lower QOL than the average person without such an injury

- focus on disability
- difficult to compare studies with the diversity of tools used

Kannisto & Sintonen (1997)	To investigate the outcome in terms of Health Related QOL of children who had sustained an SCI and were adults at the time of examination	descriptive nonrandom sample selection	N =36 mean 20 years since injury	<ul style="list-style-type: none"> 15D (investigators) 	<ul style="list-style-type: none"> the average HRQL score of the SCI group was significantly lower than the control group average importance weight assigned by SCI participants differed significantly from general population in 8 dimensions SCI rated a significantly higher importance in the domains of mental functioning, communicating, social participation & seeing and a significantly lower importance for moving, working, sleeping and eating. 	<ul style="list-style-type: none"> no opportunity to supplement items offered by investigators. no global rating of overall QOL focus on health related quality of life no understanding of how HRQL contributes to global QOL.
Krause (1997)	To generate longitudinal data on the stability of life adjustment over a 9-year period among a sample of SCI persons	descriptive nonrandom sample selection	N = 235 > 12 years since injury	<ul style="list-style-type: none"> Life Situation Questionnaire (investigator) 	<ul style="list-style-type: none"> general satisfaction significantly decreased in 10 years 	<ul style="list-style-type: none"> no global rating of overall satisfaction no opportunity to identify what was important to life satisfaction or to supplement items offered by investigators focus on life adjustment
Boswell, Dawson, Heining (1998)	To examine the meaning of life as defined by	qualitative nonrandom sample	N = 12 > 1 year since	<ul style="list-style-type: none"> Not applicable 	<ul style="list-style-type: none"> responses to meaning question: <ol style="list-style-type: none"> responses that characterized the nature of the term; subjective & changing through life span 	<ul style="list-style-type: none"> small sample size

Boswell, Dawson, Heininger Cont'd	adults with paraplegia or quadriplegia	selection	injury		<ul style="list-style-type: none"> 2) responses that provided a definition <ul style="list-style-type: none"> ● QOL domains identified: <ol style="list-style-type: none"> 1) attitude toward life; attitude changes resulting from experience of disability emerged as a significant influence 2) opportunity to work; to contribute & create through work or related opportunities 3) level of resources; wide range from basic needs, attendant care to transportation & financial income 	
Krause, Sternberg, Lottes & Maides (1997)	To identify the risk of mortality of an 11-year period as a function of psychosocial, vocational, & medical adjustment after SCI	prospective nonrandom sample selection	N = 345 11 years	<ul style="list-style-type: none"> ● Life Situation Questionnaire (investigator) 	<ul style="list-style-type: none"> ● participants expressing more satisfaction with their lives in 1985 were significantly more likely to have survived ● lower self-rated adjustment scores in 1985 were significantly associated with mortality in 1996 	<ul style="list-style-type: none"> ● no global rating of overall satisfaction ● no opportunity to identify what was important to life satisfaction or to supplement items offered by investigators ● focus on mortality & adjustment
Lundqvist, Siosteen, Sullivan, Blomstrand, Lind &	To determine which factors from the comprehensive general battery of well-	correlational nonrandom sample selection	N = 98 median 2.3 years since injury	<ul style="list-style-type: none"> ● VAS (6 cm) Schipper, Clinch, McMurry & Levit (as cited in Lundqvist) 	<ul style="list-style-type: none"> ● 60% of overall QOL rating was explained by items regarding depressive feelings, functional limitations in mobility, body-care & movement, social interaction & perception of 	<ul style="list-style-type: none"> ● phenomenon (QOL) not defined ● did not identify statement associated with scale ● no opportunity to

Sullivan (1997)	well-established questionnaires combined with the SCI-specific questionnaire constitute QOL for SCI patients	et al., 1997)	problems specific to SCI patients	identify what was important to QOL or to supplement items offered by investigators		
Kannisto, Merikanto, Alaranta, Hokkanen & Sintonen (1998)	To compare the Health Related QOL in three subgroups of SCI to study if there are differences between subgroups in relative importance assigned by them to the dimensions of HRQL	descriptive nonrandom sample selection	<p>N=36 mean 20 years since injury</p> <p>N=31 rehab not reported</p> <p>N=34 mean 4.8 years since injury</p>	<ul style="list-style-type: none"> 15 D (investigators) 	<ul style="list-style-type: none"> - all groups differed significantly in 15 D scores - highest score were in the group injured in childhood - significant difference between group with complete and incomplete injuries and between tetraplegics and paraplegics but not between any other groups - no gender differences noted - change scores from before rehab to after significant 	<ul style="list-style-type: none"> no opportunity to supplement items offered by investigators. no global rating of overall QOL focus on health related quality of life no understanding of how HRQL contributes to global QOL

<p>Kreuter, Sullivan, Dahllof & Siosteen (1998)</p>	<p>To assess & compare SCI & traumatic brain injured peers & people from general population concerning partner relationships, functioning, mood & global QOL</p>	<p>correlational nonrandom sample selection</p>	<p>N = 67 median 5 years since injury</p>	<ul style="list-style-type: none"> • VAS (0-100, very high, very low) Carlson (as cited in Kreuter et al., 1998) 	<ul style="list-style-type: none"> • singles had significantly lower QOL • no correlation between QOL and level or completeness of injury, or time elapsed since injury • no gender differences • participants with pain severe enough to interfere with daily functioning had lower QOL scores • mood, physical & social function, were significantly correlated (+) to global QOL • perceived loss of independence significantly correlated (-) to global QOL 	<ul style="list-style-type: none"> • tool adapted from a pain VAS • no opportunity to supplement items offered by investigators or to rate importance of each item
<p>Post, deWitte, Floris, van Asbeck, van Dijk & Schrijvers (1998)</p>	<p>To analyze relationships between injury-related variables, demographic variables, functional health status & life satisfaction with people with SCI</p>	<p>correlational nonrandom sample selection</p>	<p>N = 318 mean 3.6 years since injury</p>	<ul style="list-style-type: none"> • Life Satisfaction Questionnaire Fugl-Meyer, Branholm & Fugl-Meyer, as cited in Post, de Witte et al., 1998) 	<ul style="list-style-type: none"> • highest satisfaction was in the areas of contacts with friends & acquaintances, family life, and partnership relationships • lowest satisfaction was with sexual life & vocational status • respiratory problems, pain, pressure sores were significantly related to poor life satisfaction • moderate, but significant correlation between being married & better life satisfaction 	<ul style="list-style-type: none"> • no opportunity to identify what was important to life satisfaction or to supplement items offered by investigators

Post, van Dijk, van Asbeck, Schrijvers (1998)	To compare life satisfaction of SCI persons living in the community to life satisfaction of a population group	correlational nonrandom sample selection	N = 318 years since injury not reported	<ul style="list-style-type: none"> Life Satisfaction Questionnaire Fugl-Meyer, Branholm & Fugl-Meyer (as cited in Post, van Dijk et al, 1998) 	<ul style="list-style-type: none"> highest satisfaction was in the areas of contacts with friends & acquaintances, family life, and partnership relationships lowest satisfaction was with sexual life & vocational status satisfaction in only 1 of 8 domains -- self-care ability-- was significantly lower in persons with tetraplegia SCI person had a significantly higher score on family life than population No significant correlation with life satisfaction and gender, education, or time since injury had any 	<ul style="list-style-type: none"> no opportunity to identify what was important to life satisfaction or to supplement items offered by investigators
Westgren & Levi (1998)	To determine associations between major outcome variables after traumatic SCI & QOL	correlational nonrandom sample selection	N = 320 years since injury not reported	<ul style="list-style-type: none"> SF -36 Swedish Health Survey Sullivan & Karlsson, 1994 (as cited in Westgren & Levi, 1998) 	<ul style="list-style-type: none"> no significant difference in QOL related to level or completeness of injury 	<ul style="list-style-type: none"> no definition of QOL, QOL inferred from results of questionnaire no opportunity to identify what was important to QOL or to supplement items offered by investigators no global rating of overall QOL

APPENDIX B

Glossary

Table B1: Human Becoming Theory Terms and Definitions

Term	Definition
All-at-once	personal reality is cocreated with one's predecessors, contemporaries, and successors as person's continually structure meaning (Pilkington & Jonas Simpson, 1996)
Connecting-Separating	paradoxical human rhythm of moving in one direction with persons, projects and situation, while simultaneously moving away from others (Parse, 1998; Pilkington & Jonas Simpson, 1996)
Cotranscending	moving beyond the now with the emerging possibles cocreated with others and the universe (Pilkington & Jonas Simpson, 1996)
Enabling-limiting	each choice made in life means endless possibilities as well as limitations (Pilkington & Jonas Simpson, 1996)
Imaging	the shaping of personal reality through the picturing or making real of ideas or events (Pilkington & Jonas Simpson, 1996)
Languaging	expressing meaning through the giving and receiving of messages at many realms (Pilkington & Jonas Simpson, 1996)
Not-yet	multidimensional possibilities not known explicitly (Parse, 1998)
Originating	creating personal and unique ways of moving beyond in connections with persons and projects (Pilkington & Jonas Simpson, 1996)
Paradox	unity of apparent opposites; two dimensions of one rhythm which surface (Parse, 1998)
Pattern	expressions of becoming that are recognizable; continuity within the ever changing human universe process (Parse, 1998)
Patterns of relating	rhythmical ways of becoming and connecting with persons, projects, ideas, situations and objects (Pilkington & Jonas Simpson, 1996)
Possibles	the imaginables (Parse, 1998)

Powering	the pushing-resisting rhythm that propels one onward (Pilkington & Jonas Simpson, 1996)
Principle	a professed rule of action (Parse, 1998)
Project	a human creation (Parse, 1998)
Revealing-concealing	an intentional disclosing of some aspects of self , while hiding others; varies in situation to situation (Pilkington & Jonas Simpson, 1996)
Transforming	shifting the view of the familiar-unfamiliar; the changing of change in coconstituting anew in a deliberate way (Parse, 1998)
Unitary	different from the sum of parts (Parse, 1998)
Valuing	the process of choosing and living cherished beliefs (Pilkington & Jonas Simpson, 1996)

APPENDIX C

MEMORANDUM



To: Ms Janice Beitel-Wardrop
Critical Care / Emergency
Room M3113

From: Philip Hébert MD

Date: September 10, 1997

Subject: **Quality of Life for Individuals Living with Spinal Cord Injury in the Acute Care Setting**

Research Ethics Board

Room S-133, S-Wing
The Research Building
Tel.: (416) 480-4276
Fax: (416) 480-5814

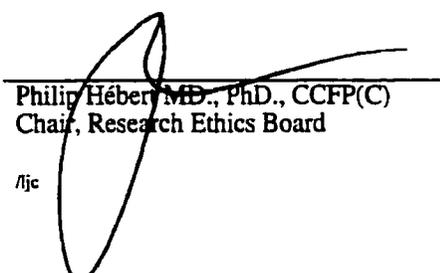
Project Identification No: 203-1997
Approval Date: *September 10, 1997*

The Research Ethics Board of Sunnybrook Health Science Centre has reviewed the research protocol referenced above on the above captioned date and approved the involvement of human subjects as specified in the protocol. A copy of the approved Information Sheet/Consent Form is attached.

The quorum for approval did not include any member associated with this project.

Should your study continue for more than one year, you must request a renewal on or before one year from the approval date. Please advise the Board of the progress of your research annually and/or any adverse reactions or deviations which may occur in the future.

The above Project Identification Number has been assigned to your project. Please use this number on *all* future correspondence.


Philip Hébert MD., PhD., CCFP(C)
Chair, Research Ethics Board

/jic

2075 Bayview Avenue
North York, Ontario
Canada M4N 3M5



APPENDIX D

Informed Consent & Information Sheet

Quality of Life: The Client's Perspective

Some registered nurses at this hospital are conducting research that looks at the way different groups of people describe quality of life. Patients who participate in the research will be given a verbal explanation of the study and a copy of this consent form.

The purpose of the research is to help nurses and other health care professionals learn about and understand the patient's perspective and improve quality of care by meeting and exceeding patient expectations. The knowledge generated by the research may help health professionals to be more aware of patients' experiences and needs.

Research with individuals living with spinal cord injury is being conducted by Janice Beitel, RN; BSN, a graduate student at the University of Toronto, Department of Nursing Science. The research is being conducted under the direction of Gail Mitchell, RN; PhD., Chief Nursing Officer at Sunnybrook Health Science Centre.

Questions about the project will be answered to your satisfaction.

Participation requires talking with Janice Beitel-Wardrop on tape about the experience of quality of life for approximately one hour. The researcher may return to ask a clarifying question(s) at a later date.

You may decide not to participate or withdraw from the study at any time without any effect on your health care at Sunnybrook Health Science Centre.

A tape recorder will be used during the interview. During the research project, the tape will be kept in locked drawer in the researcher's office. After the project is completed the tape will be destroyed.

No names will appear on the written transcriptions, reports, or published papers. The transcriptions of the tapes will be kept in a locked drawer in the researcher's office and be viewed only the researcher and her thesis supervisor.

2075 Bayview Avenue
North York, Ontario
Canada M4N 3M5

University
of Toronto

Informed Consent and Explanation Sheet, page 2

There are no specific risks related to participating in the study. The degree of risk is about the same as having a discussion with a nurse about what you are thinking and/or feeling. Indirect benefit is anticipated for other patients who receive care that is more sensitive to their needs and wants.

You are free not to answer for any reason with no affect on your health care. Should fatigue or discomfort develop in the interview, you may stop and either ask for a new appointment or cease participating.

Janice Beitel can be reached at 3348 at any time if questions or concerns come up. Gail Mitchell can be reached at extension 2778 at any time.

Having read the above information about the proposed research, I agree to participate and offer my signature as consent.

Signature

Date

Having read/or listened to above information about the proposed research, I agree to participate and offer my verbal consent.

Participant Name

Witness

Date

APPENDIX E

Data to Support Theme One – Resolving to Prevail

Table E1: Core Ideas and Concepts of Resolving to Prevail

Participant	Examples of Descriptions Given by Participants	Core Idea(s)	Abstracted Concept
1	So it's important for me to get on with it and do the best I can with it.	get on, do best I can	Resolving to prevail
	This is the first day of your life. Let's get on with it, and let's make the best out of it, first and foremost in the mind.	get on & make the best of it	
	So you need all these support groups and resources to kind of point you in the right direction. But in the end it's got to come from you.	need help, but in end it comes from you	
	I have no idea of the amount of involvement I can look forward to, but I'll tell you, I'll give it all I can, 'cause life is pretty sweet. And I think there's a lot more enjoyment ahead of me, if I let it come my way and give it a hand. So that's my short-term aim.	give it all I can and give it a hand	
	The quality of life, I guess, is mainly what you can put into it, and whatever you can get out of it. I don't think you should expect an awful lot out of it, if you don't put anything into it. I don't. I've always given everything all I've got, and I intend to keep on doing that. Quality of life is living every day as though it's the last one, and keep looking forward to the next one. No great point in looking back; the past is finished, the present counts, and the future is whatever you want to get out of it.	QOL is what you put it to it, the future is whatever you want to get out of it	
2	Well, I can't go backwards, and I've got some bets on me, and I've told you how important my family is, and I just can't give up. So I have to go forward.	can't give up, got to go forward	
	I'm looking forward to a challenge. I guess I see it as that. I have to look at it as that. If I don't, I'm sunk, you know, so... Maybe it's a challenge too. So where I take it will depend on me.	have to look as if a challenge, where I take it depends on me	

- There's no reason that I can't.. I don't think, that I can't live a com.. a happy life, just because I don't have my legs. And I have to maybe prove that to myself.
- 3 All I know is with God above, and my persistence, I'll be walking within a year. And that's just my will power. I've always been a positive thinker.
- Well, as far as what's in yourself, you just got to keep hoping, dreaming and working at it.
- Well, instead of thinking on the sad, negative side, I'll change it around and make it a happy, positive...
- I see a lot of hard work in regards to muscle toning, working out and getting this body back to the way it was. I know it's impossible, everybody's telling me it's impossible, but I'm a positive thinker, and I make impossible things possible. And if anyone knows that, it's my wife.
- 4 I'm working at rehabilitating myself. And I will. There's nothing that will stop me from doing that. You know, I'm going to [rehab], and I heard all these stories about it's going to be tough and... Well, you know what? Life is tough. And Lindhurst is just another hurdle, just a bit of a bigger jump, that's all. And I've got a lot of people behind me, and I'm going to do well over there.
- What enhances quality in my life? I think success, more than anything. I don't like to fail at anything. I don't think I've ever truly failed at anything, because I'm very persistent. But I mean, I've had to overcome a lot of hurdles in business, work, sports
- And I can lay here, sulk and cry all I want, or I can take their advice and say, hey, you've still got some living to do, you know.
- 5 I believe it's mostly in the mind, I do. I mean, your mind is what controls your whole body, you know, and yeah, I just think as positive as possible.
- have to prove it to self
- my persistence, my will power
- Resolving to prevail
- you just got to keep on
- I'll change it to positive
- I make impossible things possible
- I working at it, nothing will stop me Rehab is just a bigger jump & I'm going to do well
- I'm very persistent, I've had to overcome hurdles
- I can lay here or say I've got some living to do
- believe it is in the mind, I think positively
- Resolving to prevail

It's not that I'm happy, it's just that, you know, why should I lay in bed and just be like, omigod, I have to do this, and I'm going to be here for 6 months, or I'm going to be here for 2 years, or whatever. Like you can't do that, 'cause I don't know, it's like how you feel. I feel like I am getting better every day, you know, and what if I don't get the feeling in one of my feet

why lay in bed? it's how you feel and I feel like I'm getting better

Going forward, basically, is just what I have to do every single day, you know.

going forward is what I have to do every day

- 6 Quality of life? Quality of life. Hmm. I guess, for me, it's what I put into it, and how I accept things, deal with things, and how people around me adjust, and what I can do to make life better for myself, and what other people can do to help me. I guess that's what I think of quality of life.

Quality of life is what I put into it Resolving to prevail

Let me think. Well, I had to make certain adjustments. I mean, I'm not exactly going to go exactly the way back to the way I used to be, but if I can do everything in my power, and always put in 110% to what I'm doing, I guess I could improve my quality of life, because even though I'm limited, I still can do a lot of the stuff I could do before.

If I can do everything in my power, I can improve my quality of life

And I guess to boost my quality of life, I have to keep high spirits and high hopes that something's new over the horizon, medical technology or.. in my life, or I won't enjoy it as much.

I have to keep my hopes high or I won't enjoy it as much

APPENDIX F

Data to Support Theme Two – Considering Alternative Views

Table F1 : Core Ideas and Concepts of Considering Alternative Views

Participant	Examples of Descriptions Given by Participants	Core Idea(s)	Abstracted Concept	
1	Well, it's something to come to grips with. It's not frightening. It's a fact of life, I think, is about the best I can say.	isomething to come to grips with		
	But also, you know, you see the suffering that's going on around you. You say, well, it's no great shakes, but it could have been worse. I count myself fairly fortunate, strange as it may seem. But I do feel blessed, at least for my past life.	it could have been worse, count self as fairly fortunate		
	I wish I could explain this a little bit better, but I think it's something you probably have to experience. We often take family for granted [when not in crisis].	often take family for granted		
2	we've already talked about how it will change our lives. That doesn't mean that it's not going to be hard.	talked about how it will change our lives	Considering Alternative Views	
	I know some people, they think, well who'd want to be paralyzed, and live? I remember thinking that because I'm so active, thinking it must be awful to lose your legs. You know: I don't know what I do if I couldn't walk. But I have my arms, I can wheelchair.	I remember thinking it must be awful, but I can wheelchair		
	I have so many other riches. I have things that lots of other people don't. And those things you can't buy for whatever.	I have so many riches others don't		
	I know how I'd like to see myself in the future. Be adjusted, that I've adjusted. I still see myself meeting the school bus and putting her on the school bus with my wheelchair.	I'd like to see myself adjusted		
3	Well, instead of thinking on the sad, negative side, I'll change it around and make it a happy, positive...	instead of negative I will make it happy		

- | | | | |
|---|--|--|-------------------------------|
| | I think I used to take life for granted, and now I cherish life. You know, if I had known that this would have happened to me, I would have been a totally different person 3 years ago. But now that it's happened, it's over and done with, I find that I cherish life more. | now it's happened, I cherish life more | |
| | I have already - to respect other people for what they are. Whereas I never did that before. Like, in fact, I would look at you, I would get an opinion of you, and that was it. But people change. | I respect people for what they are now | |
| 4 | It's going to be different to enjoy life the way I did, because a lot of my enjoyment was I played many sports. But won't be able to do that now, but I'll still enjoy life. | It's going to be different but I'll still enjoy life | Considering Alternative Views |
| | I knew when I hit the pool that I'd done that much damage. And I think I've handled it pretty well, because I know now I'm working at rehabilitating myself. | I think I've handled it pretty well | |
| | You're going to be in a wheelchair for life, but there's still people worse, it's not that bad of a feeling, you know. And I can lay here. sulk and cry all I want, or I can take their advice and say, hey, you've still got some living to do, you know. And at least you can. There's people that won't, and can't. | there still people worse, it's not that bad | |
| 5 | I think differently about a lot of things I took for granted before | look at things differently | |
| | Like before the accident it'd be like, oh, I hate him - he said 'this' to so-and-so. It's just like, who cares about those stupid little things, you know? There's so many other things that you... Why would you concern yourself about that, rather than other things, you know? | who cares about the little things like before | |
| | You know, some days I'll think a little differently about things. But I'm coming to terms with it, you know, which I think is pretty important. | think about things a differently | |

- 6 Well, I had to make certain adjustments. I mean, I'm not exactly going to go exactly the way back to the way I used to be, but if I can do everything in my power, and always put in 110% to what I'm doing, I guess I could improve my quality of life, because even though I'm limited, I still can do a lot of the stuff I could do before. And my injury isn't as bad as a lot of other people's injuries are. And I guess to boost my quality of life, I have to keep high spirits and high hopes that something's new over the horizon, medical technology or.. in my life, or I won't enjoy it as much
- not going to be how I was but I can improve my quality of life
- Considering Alternative Views
- my injury isn't as bad as others
- And my physical movement, it's limited, and I even get a little bit xenophobic when I look outside and I see all the people around, how big this place is. And I never noticed it when I could walk. Now, I guess I'm more susceptible to the environment now, and more likely to catch colds, and my immune system is down from what it is, and my goals are more fragile than they were.
- I never noticed it when I could walk, my goals are more fragile now
-

APPENDIX G

Data to Support Theme Three – Dwelling with Enriching Affiliations

Table G1 : Core Ideas and Concepts of Dwelling with Enriching Affiliations

Participant	Examples of Descriptions Given by Participants	Core Idea(s)	Abstracted Concept
1	<p>Family support, first and foremost. I've have a tremendous amount of it. It's most gratifying. My wife's been here since then, and the kids, I guess, maybe 2 or 3, because they're all right here, pulling for me. I've had a lot of friends expressing their feelings, and letting me know that they're pulling for me, which is very gratifying. I find even the people at [hospital] have been extremely helpful.</p> <p>The immediate family has been here, as I say, from day one, and continues to be in touch and lend moral support. The not so immediate family is nice to have as a back-up. That's important.</p> <p>That's the type of thing I'm looking forward to: seeing the kids grow up, the grandchildren grow up. That's an experience of life. It's so sweet. It's so sweet.</p>	<p>support/ friends expressing feelings gratifying</p> <p>hospital staff helpful</p> <p>presence & being in touch lends moral support</p> <p>seeing kids grandkids grow is sweet</p>	Dwelling with enriching affiliations
2	<p>What makes my life special? Probably, my family. I had my daughter, and that's where I channeled my energy, and to my home. Somehow, as time went on, I needed other things to make my life richer, and that's where it turned inwards toward my family. And that's the most important thing to me.</p> <p>Just that the letters I got from people, the articles they wrote, the things they've said, sent and said, the comfort they've given my family, the way they've reached out and came; they call. It's the little, little warmth in my heart, like a fire, and it's there.</p> <p>So that's why I go on. That's where I want to be, and that's what's giving me the strength to go on, otherwise I might not have it. Be very despondent, I guess, or... But every time things get rough, as you know, I have that picture of my daughter up</p>	<p>family is most important makes life special daughter makes life rich</p> <p>the comfort, reaching out of people is a warmth, a fire</p> <p>thinking of daughter gives strength to go on</p>	

- | | | | |
|---|--|--|---|
| 3 | <p>Believe it or not, it was.. well, my boys [bring me comfort]. My boys, yes. My oldest daughter, yes. My wife, definitely yes. My mother, family. Most of all, my little girl.</p> <p>My wife. I couldn't do without her. I would just like rather be shot. Trying to do this on your own would be physically and mentally impossible.</p> <p>See, my kids are my life.</p> | <p>family brings comfort</p> <p>could not do it without wife</p> <p>kids are life</p> | |
| 4 | <p>And I haven't had a lot of quality of life for 2 months, except I had a lot of care and a lot of love from my family. And that's what got me through it.</p> <p>Well, my family I can't say enough about. But even if I wasn't in the hospital, they'd still show me the same love.</p> <p>But since this accident, I mean, my family's come up here and they've just been aces. I mean, treated me like a king. And they all phone me from down home, see how I'm doing. And I think it's probably brought us all closer. I think, on a whole, I'm very, very good with people. I think with the nurses, well, it may sound foolish, but I've had a very good relationship with them, and a lot of laughs, a lot of laughs, every day, and it's kept me going. But as far as personal relationships, my family comes first, and it's on a top level.</p> <p>But they always gave me hope, the whole staff here</p> | <p>family love, care provided quality of life</p> <p>family shows love</p> <p>the accident has brought family closer</p> <p>good relationship with nurses kept me going</p> <p>staff gave hope</p> | <p>Dwelling with enriching affiliations</p> |
| 5 | <p>My parents. They have been number one, actually. They've been there since day one. They're here every single day. But I know if they weren't, I probably wouldn't, you know.. 'cause when I do come down, my parents are there to bring me back up</p> <p>Had a lot of support there from the nurses; they were great.</p> <p>there's different kinds of comfort, when my parents come, that's great. Or my close friends. Or even like if I get a card from somebody. It could be the funniest card in the world and I'll cry. It's</p> | <p>parents bring me back up</p> <p>nurses provided support</p> <p>parents and friends provide comfort</p> | <p>Dwelling with enriching affiliations</p> |

'cause like it's so nice. Or flowers.

- 6 What's important in my life now? I think the most important thing to me is my girlfriend. I don't know, I couldn't.. I wouldn't have been so well if she hadn't been there. She actually.. like in London she actually pulled me out of a, like, trauma.
- Relationships that I had. Oh, first, again, is [my girlfriend] I wouldn't have been able to deal with all that I dealt with if she hadn't been there. And my parents, my relationship with my parents has really, really increased since I had the accident.
- I have relationships with some of my really good friends. But they're not even really friends. I treat them more as brothers, more than I would... I can't even describe them as best friends. They're even more than that.
- girlfriend is important and pulled me out of trauma
- wouldn't have been able to deal without girlfriend relationships with parents increased
- friends more like brothers
- Dwelling with enriching affiliations
-

APPENDIX H

Data to Support Theme Four – Bewildering Uncertainties

Table H1: Core Ideas and Concepts of Bewildering Uncertainties

Participant	Examples of Descriptions Given by Participants	Core Idea(s)	Abstracted Concept
1	It's like being in the forest, not having a clue what direction you have to go to.	like being in the forest with no clue	
	I have no idea of the amount of involvement I can look forward to	no idea of amount of involvement	
	because it's all being done for you. It's taken out of your hands. Actual control isn't all that much. But what little you have, guard it and use it to the best of your ability.	It's taken out of your hands	
2	I know I won't walk, but I can sort of come to terms with that. Maybe I have and maybe I haven't, I guess we'll see.	Maybe I have, maybe I haven't	Bewildering Uncertainties
	That's a big question mark, because I don't know what's ahead of me. I don't know what my abilities are going to be in the chair. I've never been in a wheelchair before.	It's a big question mark, I don't know	
	Well, I don't know, I've never been faced with not being a complete person. We'll have to see. I'm just going to have to try. I don't have a choice.	I don't know, We'll have to see	
3	I don't know, I'm not out there yet. I'm still here in Sunnybrook. I haven't actually got a taste of the outside world. I've been in hibernation for almost 6 weeks.	don't know, not out there	
4	I'm not sure right now, because I've never been in this position before.	not sure, never been in this position	Bewildering Uncertainties
	Now it's going to be.. going to take a lot of adjusting, for sure, and I don't know what I have to do to change the quality of my life, but all I know is we're going to work at it, and what we have is what we have.	don't know what I'll have to do	

- Well, just taking things day by day, you know, one thing at a time. Baby steps first, as they say. take things, day by day
- 5 That's a hard question [what do you see for yourself in the future]. Basically, I'm just focusing on getting myself up, getting my.. like just getting one thing at a time fixed, you know what I mean? I'm scared & excited at the same time
Like I'm totally scared to go to rehab, like totally frightened. But then, I'm totally excited at the same time, because I know they're going to start working me. that's a hard question
- what if I don't get the feeling in one of my feet? I don't know
You know what I mean? I'm here, you know. I don't know. I don't know.
- 6 I have to make a whole bunch of decisions after I leave rehab, I don't know how difficult that's going to be. I'm not really sure, but... I don't know how difficult it will be Bewildering Uncertainties
- Maybe I could do home sales or get a job outside. I don't know exactly what I could do yet. I don't know exactly what I'll do yet
-