LIVES IN TRANSITION: THE EXPERIENCE OF LIVING WITH SPINAL CORD INJURY AND THE MEANING OF ADJUSTMENT

by

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Abstract
The experience of living with spinal cord injury (SCI) is not well understood and no empirical definition of adjustment was found in the literature. Phenomenological design was used to explore these gaps. In-depth interviews were conducted with eight men and two women who have SCIs and reside in the community. The experience was found to involve a transition process wherein people moved from destabilized to restabilized identity as they progressed through phases of Disorientation in acute care, Rehabilitation, Coasting, Entering the Community, and a Critical Turning Point. As this occurred, disability became less central until finally becoming only one of many aspects of life. Support, affiliation with other people with disabilities, and a strategy of pursuing options were important facilitators of progress. Adjustment was associated with movement, change and learning. Accepting SCI was found to mean being fully cognizant of one's situation. This appeared to be an influential factor in adjustment, which findings suggest may be the course of a person's response to change. SCI as transition emphasizes the individual's perspective and introduces an alternative to the historical medical approach to SCI which focuses on the condition arising from injury. The bulk of psychological research on SCI excludes the perspectives of persons with SCI and the contexts of their lives, and it focuses on the short-term. It has not, therefore, accessed the experience of living with SCI. Transition theory seeks to understand the individual's perception of the impact of SCI on life experience over the long term. It can bring forth knowledge of SCI as an experience of living which can inform practice and further research.
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PROLOGUE

I would like the reader to approach this thesis with the knowledge that I am a person who has a spinal cord injury. In 1982 I contracted a common viral infection, and due to rare neurological side effects, I became quadriplegic. My experience since then has brought me in contact with people I may never have met who have influenced my thinking and opened my mind to ideas I may never have had. It has broadened my consciousness and taught me to appreciate that all people have a place in this world, and something to give.
CHAPTER 1
INTRODUCTION

Overview

After introducing and stating the research problem, this chapter goes on to provide a rationale for the study. A definition of the term disability, as it is used in this study, is then given, and the difficulty surrounding the definition of adjustment is briefly acknowledged. The definition of adjustment that emerged from this study is provided. Finally, the delimitations and limitations of the research are outlined.

Introduction to the Problem

This thesis demonstrates that the possibility for people with spinal cord injuries to live productive, satisfying lives, regardless of their level of physical functioning, has become a reality. Whereas in days past, an abundance of physical and attitudinal obstacles put possibilities out of reach, today the limits of potential are being challenged as many spinal cord injured persons pursue their chosen goals, however impossible it once might have been to achieve them. As a result of technological innovations, improved treatment and prevention strategies for health related issues, and improved access to both the physical and social environments, injured individuals have been able to expand their horizons. In so doing, they have become more visible members of society. Thus, a continuing spiral of positive growth has been set in motion, with a greater range of options leading to increased visibility of people with spinal cord injuries, not just in the physical environment, but in social settings as well. In turn, this promotes an increase in awareness of people with spinal cord injuries
as co-participants of society and further encourages the removal of barriers and the creation of opportunity.

Historically, medicine has viewed spinal cord injury with a defeatist attitude of hopelessness and helplessness. Citing an unknown Egyptian physician from the 15th century who described severe spinal cord injury as 'an ailment not to be treated', Guttmann (1976) says "it cannot be denied that the sentiments thus expressed have prevailed throughout thousands of years amongst most members of the medical profession in all countries" (p. 1). By the early 1940's, the situation had not improved a great deal, and although developments in medicine had made some treatment possible,

life expectancy was very short; as a rule 2 - 3 years at the utmost....Therefore, any attempt to restore a person [with a spinal cord injury] to his former social activities seemed to be out of the question and the view generally held was the sooner he died the better for all concerned. (Guttmann, 1976, p. 6)

Prior to positive advancements in medicine and technology, and in awareness and access, that today allow people to live long and well, the focus was understandably primarily on the physiological condition resulting from injury, and the physical, social and psychological ramifications of it. Current medical expertise and technology allow injury to the spinal cord to be treated and stabilized relatively quickly, and the availability of appropriate equipment and medications reduce the risk of health related problems over the long term. People with spinal cord injuries are now able to maintain consistent good health, and have greater access to both the physical and social environments. Whereas serious limitations in these areas at one time kept the
attention on the physiological condition of spinal cord injury and its
deliterious effects, it is now much more able to be directed to the
pursuit of opportunity and the achievement of meaningful life goals.
The focus has expanded beyond the condition brought about by injury,
into the realm of life experience.

Statement of the Problem

The impact of the advancements previously mentioned has
altered the phenomenon of spinal cord injury. It is now possible that
the condition arising from injury can become a peripheral concern once
people who have a spinal cord injury have become familiar with their
physical beings and have learned how to maintain good health. Thus,
for many injured individuals the dynamic experience of living with
their injury has become the dominant focus, and they have chosen to
forge ahead with their lives and pursue their life goals. A review of
the literature reveals that the approach to spinal cord injury in both
research and practice remains embedded in the medical model. From
this perspective, the condition of spinal cord injury is central, and the
experience of life as it is lived by those who have injuries is extremely
peripheral. This is reflected in the restricted, short-term focus of
rehabilitation practice, as well as in research trends.

The emphasis in rehabilitation is on teaching the physical skills
required to carry out the basic activities of daily living, such as
transferring in and out of bed, grooming, dressing, eating, and so on.
Much effort in rehabilitation is concentrated on learning how to
manage one’s immediate physical situation, and little consideration is
given to psychosocial concerns. The emphasis on physicality in
rehabilitation attests to a short-term outlook that focuses on the
physical condition arising from spinal cord injury. The lack of individuals' preparedness for return to their communities upon discharge has been noted (Carpenter, 1991, Cogswell, 1984, Oliver, M., Zarb, G., Silver, J., & Salisbury, V., 1988, Steichele, 1995). This further evidences that rehabilitation programs are not premised on a long range outlook that considers the physical and social environments individuals' will encounter as they experience living with spinal cord injury in their communities.

The bulk of psychological research on spinal cord injury has followed traditional scientific experimental methods in which operational definitions and objectivity are of central importance. Colaizzi (1978) defines an operational definition as "a means of defining a psychological phenomenon by having as little recourse as possible to human experience, and by designating that phenomenon strictly in terms of measurable, observable, and readily duplicable operations" (p. 51). In order for researchers to maintain the objective stance required by the experimental method,

Only observable, duplicable, and measurable definitions [are considered to] have psychological validity [and] ...a crucial dimension of the content of human psychological existence, namely, experience, is eliminated from the study of human psychology.....To be objective, from this perspective, amounts to using operational definitions as methodological principles that pre-establish and de-limit the content of psychological inquiry. (Colaizzi, 1978, p. 51)

Typically, isolated aspects of the condition of spinal cord injury that can be operationally defined and measured have been, and continue to be, studied. Research is beginning to devote more attention to the
importance of quality of life (Bach, & McDaniel, 1993, Craig, Hancock, & Dickson, 1994; Hanson, Buckelew, Hewett, & O'Neal, 1993; Krause, 1991) but this is yet another specific aspect that is easily measured. Without knowledge of how the life in question is experienced, the usefulness of research findings pertaining to quality of life is questionable. In addition to emphasizing the condition of spinal cord injury, the majority of research is confined to the first five years post-injury, and there is a paucity of longitudinal research.

The problem is that the experience of living with spinal cord injury has not been given adequate recognition by researchers and practitioners and, as such, it remains poorly understood. Although adjustment is a key area of concern in research and practice, it also is poorly understood due, surprisingly, to the lack of an empirically valid operational definition of the construct of adjustment. The importance of understanding the experience of living with spinal cord injury is highlighted by the fact that adjustment can only take place in the context of experience. In order to understand adjustment, one must understand the experience.

Rationale for the Study

Due to the lack of understanding about the experience of living with spinal cord injury and about the meaning of adjustment as it relates to the phenomenon of spinal cord injury, people who are either personally or professionally involved in a person's journey back to a full life after injury may be unduly limited in their ability to provide effective support. As well, people with spinal cord injuries may endure unnecessary hardship because needed supports are not available. It has been acknowledged that health care professionals have a markedly
different perspective of spinal cord injury than do those who are living with an injury (Carpenter, 1991, Trieschmann, 1988). This is reflected in the incongruency between the short-term outlook in research and practice, which focuses on the condition, and the long-term outlook of individuals who are living with spinal cord injury, whose focus has expanded far beyond the condition. It is apparent that research and practice do not concur with the experience of living with spinal cord injury. Some studies are beginning to bring forth knowledge of the experience (Carpenter, 1991, Oliver, et al., 1988, Yoshida, 1991), and the dynamics of the positive and negative turns it takes are beginning to be understood. This is crucial, for as Colaizzi (1978) states "without...first disclosing the foundations of a phenomenon, no progress whatsoever can be made concerning it" (p. 17). Without an understanding of the experience of living with spinal cord injury, the gap between the actual life experience of people with spinal cord injuries and professionals' perceptions of it cannot be closed. In addition, without knowledge and understanding of the experience, health care facilities and communities will have difficulty responding in ways that will ease the negative turns and enhance the positive ones.

In relation to the totality of psychosocial research in the area of spinal cord injury, the number of studies investigating it as a phenomenon which is lived and experienced is extremely low. Exploration of the experience needs to be emphasized more strongly in research in order to enhance understanding of life from this particular perspective. In turn, this will enhance the potential for the rehabilitation system, communities, and society in general to work in
partnership with people with spinal cord injuries for the mutual benefit of all. The dual purpose of this study was to examine the phenomenon of living with spinal cord injury from the perspective of the injured individual, and to explore the construct of adjustment as it relates to the lived experience of having a spinal cord injury. The objectives of this research were to expand understanding of the lived experience of being spinal cord injured, and to expand understanding of the construct of adjustment as it relates to the experience.

Definitions

Disability

The term disability, as it is used in this study, is understood to mean a phenomenon that is physiological in origin, and that is further constructed by society and by the meaning individuals ascribe to their disability and their experience as a person with a disability. This is the conceptualization of disability presented by Oliver, et al. (1988). Disability arises from a physiological difference that results in some deficit, whether manifested physically, cognitively or emotionally. The citizens and governments of a society are the creators of the environment in which people live. The environment can physically and socially either include or exclude people who have a disability. Thus, the inclusion and exclusion that is perpetuated by the environment represents the construction of disability by society. While it is true that disability does represent a physiological difference from the norm that results in some deficit, the impact of the deficit can be influenced by the environment. The disability arising from physiological difference is further constructed according to how the physical and social environments society creates respond to the
difference. This is the definition of disability argued by Finkelstein (as cited in Oliver, et al., 1988). Oliver, et al., (1988) draw attention to the fact that this definition lacks the essential component of the meaning individuals ascribe to their disability and their experiences as a person with a disability. This meaning uniquely constructs how an individual will define disability.

Adjustment

The meaning of the term adjustment is discussed at length in this thesis in Chapters 2, 3 and 4. This is in response to the fact that, as stated, no empirically validated, universally accepted definition of adjustment was found in the psychosocial literature pertaining to spinal cord injury. The definition of adjustment that emerged from the data in the current study is that it is the course of an individual's response to change. This is in opposition to the meaning conveyed in the literature, which suggests it is an observable, measurable state, defined by the presence or absence of certain variables. This reflects a perception of spinal cord injury as a state or condition, rather than as a lived experience.

Delimitations and Limitations of the Study

This study does not attempt to delineate the prototypical experience of living with spinal cord injury, but rather it presents one possible interpretation of the experience, based on the objective analysis of ten peoples' experiences. The results cannot be generalized, but add to the growing body of knowledge that researchers have elicited from the participants' perspective (Carpenter, 1991, Phillips, 1984, Povolny, Kaplan, Marme', & Roldan, 1993, Steichele, 1995) and
from which general common trends may become evident through future meta-analysis.

The study does not attempt to test a certain hypothesis or construct theory. Its purpose is to explore an experience, and in so doing, bring forth knowledge and insights from which new hypotheses and avenues of investigation may emerge.

Data collection consisted of interviewing each participant once, with the exception of one person who was interviewed a second time due to malfunction of equipment. The sole source of data for this study, therefore, is the interview transcripts.

Information pertaining to what was helpful to participants in their experience and what was not was communicated by virtue of these aspects of the experience being chosen as points of orientation, but it was beyond the scope of the study to examine them in detail and provide suggestions or solutions as to how to utilize what was helpful and avoid what was not. The intent of the study is to describe the experience. What was helpful to participants, and to a lesser extent, what was not, is included in that description.

Although rigorous measures to safeguard against the introduction of bias were implemented in the study, the impossibility of achieving pure objectivity must be acknowledged. Even the choice of research question reflects the researcher's bias in terms of interest and motivation in pursuing a certain investigation. This study attempts to be as objective as possible, and to make inevitable biases transparent. It is also recognized that the data is influenced by the participants' biases and memory of past events, which direct the selection of information that is conveyed.
The experience of spinal cord injury presented in this research is
cnfined to the experience as lived by young to middle aged, North
American adults, all of whom are quadriplegic. The experience of
living with paraplegia is not represented in the study. This may be
seen as a limitation, but in a study such as this with a very small
sample size, it may, in fact, be a strength in that it sets the stage for a
future comparison study. Throughout this thesis, reference is made to
the experience of people with spinal cord injuries. When this reference
relates directly to data arising from the present research, either in
conveying or discussing the results, it must be borne in mind that these
are people who have quadriplegia.

Chapter Summary

This chapter began with an introduction to the problem which
pointed out that, due to advances that have been made, people with
spinal cord injuries are much more able now to pursue their life goals
than they were in the past. As a result, the focus of attention has
expanded beyond the condition of spinal cord injury into the realm of
life experience. The problem was identified as a lack of recognition, in
research and practice, of spinal cord injury as a lived experience which
has resulted in a lack of understanding about the experience, and this
may impede the provision of effective support. In explaining the
rationale for the study it was pointed out that researchers and
practitioners hold a different perception of spinal cord injury than do
people who are living with an injury. In order for this incongruency to
be corrected, and to enhance the provision of appropriate support, a
greater understanding of the experience of living with spinal cord
injury is required. There have been only a few studies which have
investigated the experience, and there is a need, therefore, to conduct more research that will bring forth knowledge about spinal cord injury as a lived experience. The purpose and objectives of the study were stated following the rationale.

Disability was defined as a phenomenon that is physiological in origin, and is further constructed by society and the meaning people with a disability ascribe to their disability and their experience. The problem of defining adjustment was then briefly mentioned, and a definition of it as the course of an individual's response to change was provided. This is the definition that emerged from this study. Finally, the delimitations and limitations of the study were outlined, and included reference to the intent of the study, the problem of bias and the sample used.
CHAPTER 2
LITERATURE REVIEW

Overview

In reviewing the literature generated in the last fifteen years on adjustment to spinal cord injury, two trends become clear. Firstly, most studies fail to provide a comprehensive, empirically validated definition of the construct of adjustment, and secondly the bulk of the research ignores the context of the lives of people with spinal cord injuries. This chapter addresses the limitations of the quantitative research that has been conducted, created by the absence of an adequate definition of adjustment, and reviews four concepts of adjustment found in the literature. Following this, the absence of context in research studies is discussed, including identification in the literature of the need to consider context, and possible explanations for its omission. Research which does consider context is described.

Defining Adjustment

Trieschmann (1988) points out that "because what is being rated is not specified" (p. 66), much of the research on adjustment to spinal cord injury is inherently flawed. Here Trieschmann is referring to adjustment as that which is being rated. Most studies use a variety of psychometric instruments to measure certain factors researchers presume are indicative of adjustment. The Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) has often been used in studies of adjustment (Craig, Hancock, & Dickson, 1994; Nielson, 1988; Richards, 1986), and other instruments chosen to assess adjustment include The Ways of Coping Questionnaire, (Aldwin, Folkman, Schaefer, Coyne, & Lazarus, 1980), The Symptom Checklist-
90-Revised, (Derogatis, 1977), Social Support Questionnaire, (Sarason, Levine, Basham, & Sarason, 1983), Millon Behavioral Health Inventory (Millon, Green, & Meagher, 1982) and the Center for Epidemiologic Studies - Depression Scale (CES-D) (Radloff, 1977). Only one scale was found which was designed to assess overall acceptance of disability (Linkowski, 1971). For his 1969 dissertation research, Linkowski created a 50-item scale based on a theory of acceptance of disability developed by Dembo, Leviton, & Wright (1956). This theory clearly associates acceptance with adjustment, but exactly what the relationship between these two constructs is, or whether there is, in fact, any distinction between them, is not explained. Although Linkowski's (1971) scale was never published, it has been used by others (Hanson, Buckelew, Hewett, & O’Neal, 1993; Heinemann, Bulka, & Smetak, 1988, Heinemann, & Shontz, 1984), and is considered to have adequate validity.

In most of the quantitative studies, the construct of adjustment is operationalized by the researcher's choice of instruments. Accordingly, adjustment is defined by measures of depression, social support, coping, general psychological distress, and so on. Researchers do specify what they are rating; namely depression, coping, health or psychological distress. What is, in fact, being assessed, however, via these presumed indicators, is adjustment. Rosenstiel and Roth, for example, in their 1981 study of the relationship between cognitive activity and adjustment, use measures of life satisfaction, activity level, preoccupation with accident, and health and activities of daily living as indicators of adjustment. Most researchers, like Rosenstiel and Roth, have neglected to provide a core conceptualization of adjustment which
justifies their choice of criteria and the instruments used for assessment of them. Without this, there is no rationale to link certain psychometric scores to adjustment. Research appears to be based on an unstated assumption about what constitutes adjustment for people with spinal cord injuries. Most research investigates how certain factors such as depression or social support relate to this "adjustment", but credibility of results is severely diminished because the fundamental question "what is adjustment?" has been overlooked.

Four Conceptualizations of Adjustment

Value Change

Key to the theoretical framework upon which Linkowski's (1971) Acceptance of Disability Scale is based is the notion that disability, or "misfortune", as Dembo, et al. (1956) originally conceived of it, involves the loss of something which is valued. The degree of self-devaluation the injured person will experience depends on how much value is attributed to that which is lost. It follows that acceptance of disability comes about through a process of value change. The four types of value shifts originally proposed by Dembo, et al. are the same as those later explicated by Wright (1960, 1983). These are: a) enlarging the scope of values as preoccupation with loss diminishes; b) subordination of physique relative to other values (other values such as truth and wisdom become more important than physique); c) containing disability effects (preventing the spread of presumed disability effects to other unrelated areas of life - for example people who are visually impaired are also often assumed to be hearing impaired); d) transforming comparative-status values into asset values (shifting the
focus toward the value of personal attributes and away from the person's position relative to others).

According to this model, adjustment involves a reassessment of values and accepting the loss of highly valued physical ability as nondevaluating. This concept of adjustment may be useful for people with disabilities, but it is limited by its strictly intrapersonal focus. As previously stated, acceptance and adjustment are associated in this conceptualization, but the association is not made clear. Acceptance and adjustment are perhaps considered one and the same, but if this is the case, it is arguable. It may be that acceptance has a role in an adjustment process. The lack of clarity about the relationship between acceptance and adjustment further limits this conceptualization. Another shortfall of Wright's theory is that it does not explain a process whereby the value change occurs. Lending support to the theory, DeLoach and Greer (1981) have suggested that the way in which a person interprets their disability affects adjustment and that values influence the interpretation. In their review of the literature on the psychological adjustment of people with disabilities, they concluded that people who have a disability do not necessarily experience a lower level of life satisfaction than able-bodied people because they can redefine situations and adopt a value system that enables them to feel positive about themselves.

Restoring Homeostasis

According to Trieschmann (1988, 1992), the spinal cord injured person strives to restore a state of homeostasis which has been disrupted by the onset of disability. The individual attempts to regain a balance between psychosocial, biological-organic, and environmental
factors. Adjustment, she says, is a function of the interaction of person variables such as habits, self-image and coping methods, organic variables which include injury level, medical complications and age, and environmental variables like support, equipment, and architectural barriers. This definition is the most comprehensive one found in the literature. Its importance lies in the fact that the three interacting dimensions she identifies recognize the breadth and complexity of context as essential in understanding adjustment. This theory is also severely limited, however, in that it merely names the variables involved in adjustment and describes them as interacting. She does not go beyond that to provide much needed explanation and expansion of the idea of the restoration of homeostasis, in which these variables play a key role. It is unclear whether Trieschmann is suggesting adjustment is a state of balance, or the process of achieving balance. Regardless, the necessary indepth analysis describing adjustment, or in this case balance, is lacking in her theory.

**Stage Theory**

Early stage theories advocated that spinal cord injured individuals inevitably progressed through stages of adjustment similar to the stages of grieving. A unified model of adjustment to physical disability created by Livneh (1986) was based on an extensive review of more than 40 stage modes. His model suggested five stages: 1) initial impact, involving shock and anxiety, 2) defense mobilization, involving bargaining and denial, 3) initial realization or recognition, involving mourning or depression and internalizing anger, 4) retaliation or rebellion, involving externalized anger, and 5) reintegration or reorganization, involving acknowledgment or
reconciliation, acceptance or assimilation, and final adjustment, adaptation or reconstruction. Although this model is comprehensive, Trieschmann (1988) warns that the stage theories it has evolved from "are based on the clinical impressions of...particular author[s] and that no data have been presented...to demonstrate reliably and validly the existence, sequence, or duration of [the] stages..." (p. 69). Other authors (Frank, Umlauf, Wonderlich, Askanazi, Buckelew, & Elliott, 1987; Wortman, & Silver, 1989) concur that there is no empirical evidence to support stage theory, and a recent study by Buckelew, Frank, Elliott, Chaney, & Hewett, (1991) also did not support a stage theory of adjustment. Despite these negative results, within the health care system, adjustment continues to be conceptualized primarily in terms of the stage theory model which carries with it implications "that it is an all-or-nothing phenomenon with a definable end point and that there is some definable criterion which is applicable to everyone equally" (Carpenter, 1991, p. 14). Oliver (1981) suggests that the stage theory model is in accordance with what he calls the "psychological imagination" of theorists who imagine what it would be like to have a disability, and assume it would be a tragedy that "would require difficult mechanisms of adjustment" (p. 50-51). He also puts forth the provocative notion that stage theories are politically convenient. "When a disabled person fails to internalize the rehabilitation goals set by the professionals...he can be characterized as having problems in adjusting....This conveniently leaves the existing social world unchallenged [and] the goals of the rehabilitator remain unquestioned..." (p. 51).
An Idiosyncratic Process

As early as 1978, in a paper presented at the Second European Conference of Rehabilitation International, Oliver proposed a theory of adjustment which was based on a sociological theory known as symbolic interactionism, and emphasized an individualized process. This was later published in 1981. It is clear from the following explanation, that this theory "sees the individual as a free agent in his own destiny - not in the sense that he can choose whether to be paralyzed or not, but in the way he regards his paralysis" (p. 52).

The two essential components of this theory are 'process' and 'meaning' - the experiences which individuals have, the things that happen to them are not fixed or stable, but rather take the form of a process through which individuals can negotiate their own passages. Further, these negotiated passages are not determined by the events that occur (like paralysis as the result of an accident) but only by the meanings that individuals attach to these occurrences. These meanings are not themselves solely the product of individual consciousness, but are arrived at as a result of interactions with other people, close relatives and friends and the public at large..." (p. 52).

In recent years, more researchers have acknowledged adjustment as an ongoing, individualized process (Carpenter, 1991, Orbaan, 1986, Phillips, 1985, Ray, & West, 1983, Richards, 1986, Trieschmann, 1988, White, 1983). Due to the scarcity of research designed to study it as such however, this concept remains underdeveloped. It is still vague and tells us little about what adjustment to spinal cord injury means. The growing number of researchers and practitioners calling for an individualized approach to rehabilitation (Carpenter, 1991, Cogswell, 1984, Quigley, 1995, Richmond, & Metcalf, 1986, Steichele, 1995,
Whalley-Hammell, 1992) indicates increasing acknowledgment of adjustment as idiosyncratic. Bearing in mind that most of the research on adjustment to spinal cord injury is quantitative and that results are generalized, the concept of adjustment as an individualized process raises important questions regarding their reliability and validity. This, coupled with the vagueness about what exactly constitutes adjustment, suggests that the applicability of the bulk of research findings thus far may be significantly limited.

Absence of Context in Research

Studies on adjustment consistently avoid situating participants in an interactional, relational context, and keep the focus instead on how the many implications of spinal cord injury affect the individual alone. According to several authors (Carpenter, 1991, Oliver, 1981, Trieschmann, 1992), "adjustment is seen as largely an individual phenomenon, a problem for the person with the disability and, as a consequence, the support group context and the wider social context are neglected" (Carpenter, 1991, p. 14). Oliver (1981) comments that a stage theory model, in its assumption that adjustment comes about by the individual passing through a series of fixed stages, conceptualizes adjustment as an individual phenomenon, "a problem for the disabled individual" (p. 50). This model has been firmly entrenched both in theory and practice and it is only recently that research has begun to challenge its validity (Buckelew, Frank, Elliott, Chaney, & Hewett, 1991, Frank, Umlauf, Wonderlich, Askanazi, Buckelew, & Elliott, 1987, Wortman, & Silver, 1989). As such, this has permitted a continued emphasis on the individual's psychological reaction to disability and the omission of context. As early as 1976, Shontz called for the
inclusion of context in an address to the American Psychology Association regarding disability and psychological adjustment. This was published in 1977. Although his comments pertain to psychological adjustment, they highlight the importance of recognizing context. He points out that disability is only one factor affecting an individual's life situation and that fully understanding psychological reactions to disability "requires the understanding of individual human beings in all their complexity" (p. 130). Researchers and practitioners recent advocacy of individualized approaches to rehabilitation (Carpenter, 1991, Whalley-Hammell, 1992, Quigley, 1995, Steichele, 1995) indicate a recognition of the inescapable influence of context in adjustment and bring attention to the need to understand the individual with a disability in their full life's context.

Although there appears to be movement towards a much broader, inclusive conceptualization of adjustment, the general trend in the research has been to study individuals in isolation from the context in which they live. Yet, with or without disabilities, people are interpersonal beings constantly interacting with their social and physical environments, being affected by them, as well as having an effect on them. The value of studies that do not take this into consideration in the exploration of adjustment are questionable. Unless adjustment is seen as a purely intrapsychic phenomenon, as it is in the stage model which is increasingly being rejected, context must be considered in research aimed at furthering an understanding of adjustment.
Interactional Perspectives of Disability

While some authors do note the exclusion of environmental variables (Krause, & Dawis, 1992; Trieschmann, 1988), others go further and stress the need for research that addresses the mutual interaction between people with disabilities and the social and physical environment (Hahn, H., 1984, Lilliston, 1985, Mackelprang, & Hepworth, 1988). Hahn (1984) understands disability as "an interaction between the individual and the environment rather than something primarily within the person" (p. 362). In their study of the social and emotional adjustments of spinal cord injured individuals, Mackelprang and Hepworth (1988) began with the premise that "the extent of disability...is reciprocally determined by transactions between people and their environments rather than residing exclusively within the individual" (p. 24). They further acknowledge that disability is minimized by the extent of "goodness of fit" between the needs of the person with the disability and the environmental resources.

Goodness of Fit

Coulton (1981) refers to person-environment fit, which she defines as "the degree of congruence or correspondence between an individual's needs, capabilities, and aspirations and the resources, demands and opportunities characteristic of the environment" (p. 26). Referring to the responsibility social workers have to make a thorough "biopsychosocial" assessment of their clients' needs, physical, psychosocial, behavioral and economic dimensions of the person-environment fit must be considered. Interventions to increase person-environment fit can include both changes in the person as well as modifications of the environment.
A Psychosocial Model

Roth (1987) identifies three models of disability, all of which accentuate what the individual with a disability is not capable of achieving. "The functional limitation, economic, and medical models all define disability by what a person is not - the medical model as not healthy, the economic model as not productive, the functional limitation model as not capable" (p. 434). Alternatively he presents a psychosocial model according to which "what is significant [about disability] can be revealed only by the ecological framework in which the disabled person exists" (p. 434). This framework includes "interactions through which society engages a disability" (p. 434), attitudes others hold, architecture, and transportation.

Explaining the Absence of Context

Although Hahn (1984) stated that increasingly disability was becoming seen as a social, economic and political issue rather than "a collection of individual problems" (p. 362), studies have remained predominantly focused on isolated aspects of disability. The research fails to explain the bias toward this focus, but several explanations seem worthy of consideration.

Participant Availability

One possible explanation for the emphasis on the individual in the study of adjustment may be the simple logistics of availability of participants. Very often they are inpatients of hospitals or rehabilitation facilities and as such, are either temporarily removed from their usual community environment or have not yet left the rehabilitation setting.
Person Attribution

Wright (1983) offers another explanation for researchers' emphasis on the personal aspects of spinal cord injury, based on the natural human tendency to attribute the cause of behavior to the person, especially when the behavior is atypical. "If explanation of the behavior in question...can be found in the presumed characteristics of the people observed, person attribution takes place" (p. 42). To assume that the problems people with disabilities encounter arise solely from their disability is shortsighted, and the research, confined as it is to studying the personal realm, is similarly shortsighted. The body of research that exists in the area of adjustment to spinal cord injury is large, but the focus is narrow.

Sickness Treatment Model

It is possible that this restricted focus also stems from what Trieschmann (1988) refers to as the seduction of psychology by the sickness treatment model. The predominant approach of the adjustment research is structured according to several characteristics of this model, as it is presented by Trieschmann (1988). These are outlined as follows.

Acute Orientation

Research is often conducted during the rehabilitation phase of treatment. Follow-up studies are few and far between (Craig, Hancock, & Chang, 1994, Crewe, & Krause, 1990, Hanson, Buckelew, Hewett, & O'Neal, 1993) and longitudinal designs are rare (Hancock, Craig, Dickson, Chang, & Martin, 1993, Krause, & Dawis, 1992). It has been pointed out that problems associated with disability may become evident months or years after the event (Krause, 1992, Krause, &
Dawis, 1992, Tait, & Silver, 1989) and as such, research designed to accommodate a protracted time span could considerably broaden the understanding of the disability experience.

**Analysis Into Parts**

Research addresses a wide array of issues that may become salient as a consequence of spinal cord injury. Vocation, sexuality, relationships, depression, self-concept, self-blame, locus of control, ways of coping, self-neglect, life satisfaction, quality of life, social support, and self-esteem have all been the focus of research, with depression and self-blame having been studied extensively. Shontz (1989) notes that, although informants participate in such studies, the "real subjects of interest...are variables, outcomes, or behaviors, not persons" (p. 169).

The purpose of some research that studies specific variables appears to be to contribute to theoretical debate rather than to advance knowledge of adjustment to spinal cord injury. The adaptiveness of self-blame, for example, has been argued since Bulman and Wortman's (1977) study. Their results indicated that self-blame was associated with good coping. Reliance on subjective staff ratings, however, constitutes a serious weakness of the study. Schulz and Decker (1985) investigated the relationship of self-blame and long-term adjustment and found that 20 years after disability onset only a moderate correlation was evident. Heinemann, Bulka and Smetak (1988) found similar evidence that self-blame may be adaptive immediately following injury but "it appears to no longer serve this function after several years" (p. 204). Nielson and MacDonald (1988) found that self-blame was associated with poor coping. More than a
decade and a half after the first investigation of self-blame, its influence on adjustment is still unclear.

Similarly, a debate is ongoing regarding the adaptiveness of depression following spinal cord injury. Frank, Elliott, Corcoran and Wonderlich (1987) have written a thorough review of the extensive body of literature related specifically to depression and adjustment. They conclude that studying depression as a discrete phenomena may be of limited usefulness. They suggest it may be more helpful to view it as "an interaction among several possible life systems" (p. 625) which may include "previous coping abilities, life experiences, current coping resources, social support systems, and interpersonal environments during and following rehabilitation" (p. 623).

Fragmented Approach

Research is generally designed to study distinct aspects of the experience of living with a disability and rarely attempts to examine the experience as a whole (Laskiwski, & Morse, 1993). Phillips' (1984) narrative exploration, Povolny, et al.'s (1993) case study, Murphy, et al.'s (1988) ethnography, Carpenter's (1994) phenomenological research and Steichele's (1995) focus group research on the stressors involved in living with a spinal cord injury, were the only studies found which were designed to investigate the whole. Heinemann and Shontz (1984) wanted to examine the experience of adjustment from the "insider's" perspective but only as it related to the evaluation of a process model of adjustment. They used qualitative design to investigate the extent to which adjustment proceeds in a sequential manner and the extent to which it follows characteristic preinjury patterns.
The majority of the research uses instruments such as questionnaires, scales and inventories to assess independent variables hypothesized to be relevant. Research design which incorporates the use of psychometric measures confines subjects' experience within the parameters of the instruments used. As such, valuable information may be left undisclosed.

Overwhelmingly, a correlational design is used in the study of adjustment. Since causation cannot be determined from the existence of a correlation, results can only be speculative. Craig, Hancock, and Dickson (1994), for example, attempted to isolate factors associated with depression two years post-injury. Results indicated that pain was predictive of depression but the direction of the relationship could not be determined. It was unclear whether depression exacerbated or caused pain or whether pain caused depression. Despite the inconclusive nature of some results, interesting questions for future research often evolve out of correlation studies. In Taricco, et al's. (1992) study of the relationship between functional status, perception of adjustment, occupational outcome and social functioning, a surprising lack of association between functional status and occupational outcome was found. They tentatively suggested that other factors might affect the likelihood of the person with a disability keeping his or her pre-injury occupation. The interesting question generated by this research is, what are these factors?

**Professional as Source of Knowledge**

Few would argue with the assertion made by Lane (1992) that "people with disabilities are the experts of what it means to live with disability" (p. 53). Although there is a growing recognition that the
perspectives of spinal cord injured persons need to be emphasized more in the literature (Carpenter, 1991, Steichele, 1995) there are still very few studies which contribute in this way. Despite the obvious benefit of having input about the experience of spinal cord injury from those who are living through it, the main source of knowledge is the professional in the health care field who continues to determine the direction of research and seldom solicits input from people with spinal cord injuries.

Social Isolation

Trieschmann (1988) suggests that the phenomenon of professionals being virtually the sole sources of knowledge indicates that a social isolation exists between them and people with spinal cord injuries. She includes herself among professionals who, without knowledge of the experience of living with a disability, determine the needs of people with disabilities. Not surprisingly, this has created a gap between the needs of people with disabilities and the services provided.

Consumers have little say as to what will be the content of research into the nature or course of their disabilities. We professionals who are not experiencing those disabilities determine what needs to be studied....We professionals often believe in a reality that is so very different from the reality that is lived by people with disabilities, and because of our social isolation from them, we seldom realize how wide the schism is. (Trieschmann, 1988, p. 35)

Based on her experience in the rehabilitation field, and her social and professional relationships with spinal cord injured persons, Carpenter (1991) believes also that "most health professionals are personally and
socially isolated from the people [they] serve" (p. 190). She agrees that there is "a major discrepancy between the perception of spinal cord injury and its consequences held by health professionals, and those of people who experience the injury over a period of time" (p. 9).

Evidence of Social Isolation

**Determination of research.**

Several authors (Cairns, & Baker, 1993, Frank, Van Valin, & Elliott, 1987, Frank, Elliott, Corcoran, & Wonderlich, 1987) point out that assumptions based on early impressionistic reports of clinical experience and observations typically guide research. Rather than consulting people with spinal cord injuries for insight as to what research would be most useful, professionals rely instead on assumptions derived from subjective observation. Thus a detachment from spinal cord injured peoples' experience of life is maintained. Research which investigates the experience of living life with a spinal cord injury is still sparse. As previously discussed, knowledge of the disability experience arising from research is often restricted by the researcher's choice of a quantitative design and the use of instruments.

**Language.**

A division between what Wright (1983) calls the insider (the person experiencing the behavior) and the outsider (the person observing the behavior) is still occasionally expressed in the literature. Mackelprang and Hepworth (1988) repeatedly refer to people with spinal cord injuries as "these people". The purpose of rehabilitation, Trieschmann (1988) says, is to teach people "to live with their disability in their own environment" (p. 26). Her phraseology suggests separation. She points out that people with disabilities must be taught
social skills that will enable them to function self-sufficiently in society, and that the onus is on them to put others at ease. No reference is made, however, to the role of society in the adjustment process. Carpenter (1991) and Trieschmann (1989) both point out that, in terms of the dominant medical model of health care delivery, responsibility for success rests solely with the person with the disability.

Spinal cord injured persons are still sometimes accorded victim status in the literature, and their disabilities described in negative terms such as it being a burden (Taricco, et al., 1992) or a penalty (Trieschmann, 1988). This use of language serves to reinforce the personal tragedy view of spinal cord injury concocted by researchers' "psychological imagination" (Oliver, 1981). After a lengthy description of "the devastating consequences" of spinal cord injury related to the loss of the "former body", Laskiowski and Morse (1993) write that a rehabilitation staff member involved in their ethnography of a spinal cord unit noted 'sadly' that everything changes for the injured persons. While the loss associated with spinal cord injury most certainly is sad, the way it is presented in their article strongly suggests becoming a person with a spinal cord injury is very much a personal tragedy. The subtle use of language can help maintain a separation between those who have spinal cord injuries and those who do not, or even more subtly create division between those who have been struck by tragedy and those who have not.

**Subjective staff ratings.**

There are numerous references in the literature to a reliance on subjective staff ratings for the assessment of adjustment (Bulman, &
Wortman, 1977, Dunn, 1977, Frank, Elliott, Corcoran, & Wonderlich, 1987, Van Den Bout, Van Son-Schoones, Schipper, & Groffen, 1988). In Dunn's (1977) study, five rehabilitation staff members were asked to formulate their own definition of overall adjustment and rate participants accordingly. Definitions were based on a variety of characteristics, including physical ability, ability to handle people and likability. The extremely subjective nature of these ratings certainly call their validity into question. Van Den Bout, et al. (1988) asked a rehabilitation physician, nurse and psychologist to provide ratings of coping. Interreliability coefficients for physician and nurse ratings were moderately high, but coefficients for the psychologist and nurse, and psychologist and physician were low. This inconsistency highlights subjective bias in the ratings which is a severe weakness in the design. The inconsistency seems to have been dealt with simply by discarding the psychologist's ratings. In their review of depression after spinal cord injury, Frank, et al. (1987) point out that evidence exists to suggest that "staff overestimate the degree of depression and distress patients experience" (p. 619) and that depression is overdiagnosed due to reliance on subjective criteria. Other research has confirmed that a discrepancy often exists between how staff and patients perceive the patient's psychological state (Bodenhamer, Achterberg-Lawlis, Kevorkian, Belanus, & Cofer, 1983, Cushman, & Dijkers, 1990, Ernst, 1986). A possible explanation of the disparity between staff ratings and subjects' experience is Wright's (1983) concept of "the requirement of mourning."

When people have a need to safeguard their values they will either insist that the person they consider
unfortunate is suffering (even when that person seems not to be suffering) or devaluate the unfortunate person because he or she ought to suffer and does not. (p. 78-79)

This theory goes hand in hand with the personal tragedy view of spinal cord injury, and provokes thought about the motivation to see it in such a framework.

Caplan's (1983) study found that not only was there a lack of congruence between staff and patients' ratings of patient mood, but there was also a high level of intrastaff discordance in the ratings. This could not be explained by the amount of contact between staff and patients. Caplan suggests that the kind of contact and the context related to it may be factors associated with the differences among staff ratings.

Research results.

Studies investigating the phenomenon of social isolation, or insider/outsider division, are rare. One study conducted by Murphy, et al (1988) found that "the apartness of the disabled...has much larger dimensions than mere accessibility, and their lives within the recesses of society are not so much matters of choice as the result of deliberate exclusion by others" (p. 238). Murphy, et al's thesis is that indefiniteness of people with disabilities arises from society's perception of them as being somewhere between sickness and wellness. They may not need medical care but at the same time they cannot walk, so a perception exists that they "can hardly be called 'well' either" (p. 238). Society deals with this by avoidance, which leads to exclusion. What is strongly implied here, is that the criteria for wellness and inclusion is normality or sameness.
The value of "normality".

Wright (1983) states that "adjustment is often judged in terms of how skillfully the normal state is emulated" (p. 23-24). The goal of rehabilitation, Trieschmann (1988) says, is to train "the person with a disability to achieve his maximum potential for normal living..." (p. 26). One of the themes that emerged consistently in Phillip's (1984) study was the notion that persons with disabilities should try harder to overcome barriers and achieve normality.

Phillips addresses the issue of the dilemma of normalization in a report published in 1985, based on her study. Rehabilitation professionals, she says, encourage people with disabilities to adjust to society. The dilemma people with disabilities are faced with is "how to maintain a positive self-image and achieve personal success, while striving for a successful social image in a society which is reluctant to accommodate...their physiological differences" (p. 50). She notes that the goal of successful rehabilitation is normalization but that her informants have their own definitions of success. These are identified as acquiescence, normalization, adaptation, renegotiation and inversion. Inversion refers to inverting "social stereotypes about appropriate disability-related behavior" (p. 54). Each of these strategies is illustrated in the participants' narratives, with most informants making use of all five, depending on the context and the desired accomplishment. Whereas researchers typically impose definitions of success on the person with the disability, Phillips (1985) acknowledges that "disabled persons must self-determine their social and personal goals, and, therefore, their own definitions of success" (p. 48).
Inclusion of Context

Studies which focus on the experience of people with spinal cord injuries living in the community appear to be relatively rare. Phillips (1984) collected personal experience narratives from 33 people with disabilities using informal interviews and open-ended questions. Although she does not explicitly state that all of her informants lived in the community, as opposed to being in a rehabilitation facility, it is clear that the large majority were active in the community. Thirteen were employed and ten were full-time students. The narratives provided by Phillips' informants revealed that many of their experiences were shaped by a societal belief that people with disabilities are "damaged goods". Interaction between subjects and nondisabled persons was characteristically shaped by this preconception.

Povolny, et al. (1993) used a case study format to investigate the effect of spinal cord injury on the lives of two women who had returned to the community following rehabilitation. Using unstructured interviews they gathered information which illustrated how becoming disabled had affected certain aspects of the participants' lives, such as family relationships and spirituality. Interestingly, both participants identified a specific event which "was a turning point in their acceptance of disability" (p. 33). After these events had occurred, one participant realized the need to make life changes and began setting goals, and the other "emotionally grasped that she could only go on with her life" (p. 33).

Murphy, Scheer, Murphy, & Mack (1988) conducted a three year ethnographic study of paraplegics and quadriplegics. This participant-
observer research focused exclusively on people living in the community outside the hospital setting. Their analysis puts forth the provocative concept of people with disabilities as liminal people, those who "have been declassified but are not yet reclassified" (p. 237). Their observations led them to the conclusion that people with disabilities remain socially undefined and distanced.

Carpenter (1994) used a qualitative design to study how people with spinal cord injuries "conceptualize the experience of spinal cord injury over the years" (p. 616). She defines experience as "the act of living through, and involvement with, the event of spinal cord injury and its consequences" (p. 616). Using open-ended questions designed to encourage participants to express the meanings they gave to the experience of spinal cord injury, she interviewed ten participants who were self-defined as successfully rehabilitated. Her findings suggest three categories in the participants' descriptions which are characteristic of the spinal cord injured individual's experience. The first is rediscovering self, in which an experiential split between one's mental and emotion self-image as an able-bodied person and the new physical reality is gradually reconciled. Secondly, she notes a redefining of disability in which individuals challenge disability stereotypes held by society and formulate their own unique perception of disability. They become confident with their abilities and see themselves as the experts in control of their lives. The third category she identifies is establishing a new identity in which characteristics of self-concept which are no longer applicable are relinquished and replaced by others which are more appropriate. This study is valuable in that it increases understanding of the changes spinal cord injured
persons experience as they integrate their experience of disability into their daily lives. It is one of the few studies in which injured individuals are given the opportunity to express their experience of responding to disability from the rehabilitation phase right through to successful life in the community.

Steichele (1995) conducted a focus group study to identify the stressors associated with spinal cord injury from the perspective of injured individuals living in the community. The importance of her research lies in the insight it provides into the experience of living with spinal cord after discharge from rehabilitation. This crucial area of understanding has been virtually ignored by quantitative studies which are so often tied to the rehabilitation or hospital setting, and conducted by practitioners in the rehabilitation field. She acknowledges her study does not give a full picture of the experience in that its examination of stressors evoked a portrayal that was slanted toward the negative. It is highly valuable, however, in terms of helping to fill the gap in services she, and others (Carpenter, 1991, Oliver, et al.,1988, Vargo, 1982), identify. It contributes to knowledge of much needed improvement in preparing individuals for the transition from rehabilitation to community life and supporting them through it. Her work adds to the growing call by researchers (Carpenter, 1991, Quigley, 1994, Steichele, 1995, Whalley-Hammell, 1992) for more individualized rehabilitation programs, advocated as early as 1968 by Cogswell in research that was reprinted in 1984.

Chapter Summary

This literature review has shown some significant deficiencies in the research on adjustment to spinal cord injury. In particular, the
construct of adjustment was not found to have been adequately defined by most researchers. As such, research has proceeded without a clear understanding of what is meant by adjustment. A strong bias toward studying people with spinal cord injury in exclusion from the physical and social environment was also found. Without the inclusion of this essential dimension of life, knowledge of their experience can be broadened only so far. In addition, the perspectives of people with spinal cord injuries are all but absent, in favor of those of the professional "experts". Spinal cord injury is thus represented as a certain state of affairs rather than a person's ongoing experience, and the emphasis is on investigating particular effects of it; not on understanding how it is experienced. Knowledge is confined therefore, within the parameters of what effects researchers consider meaningful. Ironically, however, without a fundamental understanding of the experience, researchers have no way of accurately determining whether their research is relevant. The favoured choice of quantitative designs and the reliance on psychometric measures have also contributed to greatly limiting the expansion of insight into the experience of living with spinal cord injury.

Research Questions

In view of the gaps identified in the literature, this study will explore the following questions.

1. What is living with a spinal cord injury like?
2. What has been helpful in the experience and what has hindered?
3. What does adjustment mean for persons living with spinal cord injury, in terms of their experience of living with spinal cord injury?
CHAPTER 3
METHODOLOGY
Overview

This chapter provides a detailed rationale for the choice of research method, followed by an explanation of phenomenology and the concept of lived experience. The issue of credibility in qualitative research is discussed, and the means used to ensure its strength in this study are outlined. Researcher bias is addressed, and includes a statement of my biases, as well as my definition of adjustment. My conceptualization of disability, which is also shaped by my biases, is described. The procedure followed in this study is then outlined, and includes descriptions of selection criteria and recruitment, the research sample, and the interviewing process and format. A description of the objectives of data analysis in phenomenological research is provided, and the steps taken in analyzing the data collected are outlined.

Rationale for Choice of Method

It has been pointed out that in choosing a methodology, researchers should determine whether underlying assumptions associated with quantitative or qualitative research fit with the phenomenon under study (Guba & Lincoln, 1981, Schumacher & McMillan, 1993). While this is an essential consideration, the researcher's philosophical stance toward the phenomenon is also an important determining influence. I believe it is necessary when studying social-behavioral science that researchers question their philosophical orientation to a phenomenon, as well as the ultimate objective of their inquiry. If, indeed it is to both "advance knowledge and (italics mine) improve practice" (Schumacher & McMillan, 1993, p.
16) it is imperative that they ask whether their orientation facilitates or limits achievement of that objective, and how it does so. Although the general view of researchers is not overtly stated in the literature, it is communicated through the choice of method, in that method prescribes the focus, form and content of research. It is too simplistic to say that the extensive use of quantitative methods in spinal cord injury research is merely a result of preference. As Schumacher & McMillan (1993) point out, the terms quantitative and qualitative refer not only to research methods; they "refer to distinctions about the nature of knowledge: how one understands the world and the ultimate purpose of research" (p. 14).

The bulk of the psychological research on spinal cord injury reflects a logical positivist philosophy which assumes a single objective reality. From this perspective the world is seen as "a series of real entities and steady processes, all of which are fragmentable into a series of independent subsystems" (Guba & Lincoln, 1981, p. 56). Rather than being seen as a connected whole, the world is seen in terms of disconnected parts. Quantitative research, with its emphasis on prediction and control, aims to establish universal context-free generalizations by creating and adhering to designs which eliminate the effects of confounding variables. The influence of environment must be neutralized through the use of controls, and environmental context, except as it exists within the parameters of the study, is eliminated from the realm of inquiry. "People and their environment are seen, in effect, as two separate and distinct things or poles" (Valle & King, 1978, p. 7). Interactions between researcher and participants are also controlled in order to eliminate confounding effects, and to
enforce the assumption that the researcher has no influence on the phenomenon under study, and vice versa. The relative absences of context and participant perspective in the literature on spinal cord injury is not simply due to the use of quantitative methods, but further it reflects researchers' perceptions of spinal cord injury at a philosophical level. It is seen as an entity that exists "in" the world, rather than being "of" the world, that is fragmentable into parts, and that remains outside researchers' realms of experience by virtue of their purposeful detachment from it.

As a person living with a spinal cord injury, I am inseparable from it and therefore, it does not, from my perspective, exist as an entity. Rather it is one aspect of my multi-faceted reality, interwoven with every other one, into the entirety of my experience. To extract it is impossible, and to isolate it and examine it separately renders it practically meaningless. Guided by my perspective on spinal cord injury, I chose to use qualitative methodology, which is most often associated with a naturalistic-phenomenological philosophy. Rather than a single objective reality, the assumption underlying the qualitative paradigm is that multiple, interrelated realities exist. Each one is recognized as providing a unique perspective which cannot be evaluated comparatively in terms of truth value. Phenomena do not converge into one single form but instead are seen to diverge into many complementary and interwoven forms.

All research is concerned with furthering understanding, but rather than the focus of understanding being restricted to prediction and control, qualitative research is oriented to discovery and seeks to expand understanding of a phenomenon by recognizing its complexity
and delving more deeply into it. Naturalistic inquiry assumes "that all phenomena are characterized by interactivity" (Guba & Lincoln, 1981, p. 58) and the interaction between researcher and participant is acknowledged, allowing the researcher to become immersed in the phenomenon under study. With the recognition of the interactive nature of the many dimensions of a phenomenon, qualitative research includes context as an essential component (Jensen, 1989). As such, generalizations, which by their very nature must be context-free, cannot be made. Instead, working hypotheses, which can be assessed for their degree of "fittingness" with other contexts, are generated (Guba & Lincoln, 1981). A working hypotheses is a proposition that arises from and is supported by a specific investigation (Guba & Lincoln, 1981). Whether or not it fits within a different context requires thorough knowledge of both the original context from which it is derived as well as that to which it is being applied. What is needed in order to assess fittingness is referred to as thick description (Guba & Lincoln, 1981) and is described by Van Manen (1990) as "interpretive descriptions that exact fullness and completeness of detail, and that explore...the fundamental nature of the notion being addressed" (p. 17). In order to reflect the full complexity of a phenomenon, literal description must extend to include interpretation of meaning in terms of values, attitudes, motives and so on. Qualitative methodology, structured according to the preceding assumptions, allows me to abide by my personal orientation and investigate spinal cord injury as the complex, interactive, multi-dimensional life experience I understand it to be. Unlike quantitative research which is highly structured, singular and reductionist, qualitative research is open, inclusive and
expansionist, and facilitates in-depth exploration of the experience of spinal cord injury.

For researchers who view a phenomenon as a part of an inter-subjective, multi-layered and interconnected reality, it can only be adequately understood in the context of greater understanding of that total reality (Barnes, 1992, Guba & Lincoln, 1981, Van Manen, 1990). In such a framework, if investigation of psychological phenomena is to be meaningful, research must first endeavor to "descriptively identify what each phenomenon is" (Colaizzi, 1978, p. 57). It is evident from the way in which spinal cord injury research has traditionally been conducted that it is approached much more as a physical phenomenon with secondary psychological and social effects, rather than a life experience that begins with a physical change, and is characterized by interactive physical and psychosocial components. As such, research has attempted to describe spinal cord injury in terms of individual effects, disconnected from each other but collectively attached to its physical nature. The bulk of research has been conducted in a medical/rehabilitation setting within a short time post-injury, and has relied on restrictive quantitative methods. Researchers have rarely extended the focus of study beyond these boundaries to encompass years of post-rehabilitation community living. The insight necessary to describe the experience as a complex, fluid, whole cannot be accessed in this way and therefore the phenomenon of spinal cord injury has not been adequately identified and remains poorly understood.

The limited ability of quantitative method to expand understanding about the experience of living with spinal cord injury is due, in part, to the requirement that subjects respond in a highly
controlled manner to only that which the researcher specifically asks. As such, it is the researchers' perspectives of spinal cord injury that lead the investigation and are reflected in the results. What the quantitative studies collectively present are researchers' various, disconnected ideas related to having a spinal cord injury, and the voices of the individuals who are living with spinal cord injuries who already have the knowledge and can best enlighten others, are all but absent. A primary concern in my choice of method, therefore, was that it facilitate a description of the experience from the spinal cord injured person's perspective.

Hermeneutical phenomenology, with its emphasis on the description and interpretation of lived experience, is best suited to realizing the purpose of the study and meeting its objectives. In its purest form, lived experience is our experience as we are engaged in living it minute by minute. It is our "immediate, pre-reflective consciousness of life: a reflexive or self-given awareness which is, as awareness, unaware of itself" (Van Manen, 1990, p. 35). Through description, phenomenology attempts to get as close as possible to the prereflective experience, while recognizing that it is impossible to make direct contact with it. Van Manen (1990) describes the consciousness associated with lived experience as a non-reflective presence to what one is doing, and it is only through reflecting on that experience that it can be grasped. Living through an experience and reflecting on it cannot occur simultaneously and thus, "reflection on lived experience is always recollective" (Van Manen, 1990, p. 10). Phenomenological description includes not only concrete experience but also attempts to describe the meaning assigned to it through...
"meditations, conversations, day dreams, inspirations and other interpretive acts" (Van Manen, 1990, p. 37). In this way, lived experience gains hermeneutic significance. Phenomenology transforms "lived experience into a textual expression of its essence....[that] is at once a reflexive re-living and a reflective appropriation of something meaningful" (Van Manen, 1990, p. 36).

It is clear that, in a phenomenological study, the participants are the acknowledged experts. This method allows the focus to be shifted away from the professional as the source of knowledge and be put on the participants. As Fischer (1978) states, phenomenology attempts to understand the general psychological meaning of some particular human way of being-in-a-situation, ... through a number of descriptions of this way of being-in-a-situation from people who have lived through and experience themselves as so involved. (p. 177)

The use of phenomenology in the study of spinal cord injury also narrows the distance that exists between researchers and participants. It calls for researchers to be interactive with participants who, in effect, become co-researchers and may be consulted numerous times during the course of a study to discuss new, emerging insights, or to clarify or expand on information already collected. As discussed in Chapter 2, researchers typically maintain a separateness from their participants and attention has been drawn to the fact that as a result, their perceptions of spinal cord injury and the perceptions of those who are living through the experience are significantly different (Carpenter, 1991, Triechmann, 1988). Phenomenology, with its emphasis on inclusivity, has the potential to correct this discrepancy, first as it exists between researcher and participant, and ultimately as
it exists in the general population between people with and without spinal cord injury. Van Manen (1990) says, "Phenomenology does not offer...the possibility of effective theory with which we can now explain and/or control the world, but rather it offers...the possibility of plausible insights that bring us in more direct contact with the world" (p. 9). The world as he speaks of it is the single world all human beings inhabit, as opposed to a particular "world" represented by a research sample. As he states,

The point of phenomenological research is to "borrow" other people's experiences and their reflections on their experiences in order to better be able to come to an understanding of the deeper meaning or significance of an aspect of human experience, in the context of the whole of human experience. (Van Manen, 1990, p. 62)

Phenomenology attempts to discover understanding by inquiring into the nature of phenomena as it is meaningfully experienced. As such, it is an extremely effective method for addressing the research problem I have identified and achieving the objectives of this study. Furthermore, it is a method that is highly congruent with my philosophical outlook on the world and my personal values of acknowledgment of experience and inclusiveness.

Credibility

The qualitative research design is flexible and allows for changes to be made as the course of inquiry proceeds and new insights become evident, and instead of collecting data using instruments with proven reliability and validity, the researcher is the instrument and therefore, has active involvement in the study through interaction with participants. This seeming freeform style does not compromise rigor
and credibility, but it does require that careful attention be given to them for the duration of research, from the planning stage through to completion of the written description. From the outset I was aware that my research topic was intensely personal and that I was emotionally connected to it. I had an insider's perspective and I had strong feelings about certain aspects of my own experience that I knew had the potential to obscure my ability to be objective. My efforts to strengthen and protect the credibility of this research began by being constantly mindful of "objectivity", defined by Colaizzi (1978) as "fidelity to phenomena" (p. 52). As he states, if a person is objective then "his statements faithfully express what stands before him, whatever may be the phenomenon that he is present to" (p. 52). In attempting to maintain objectivity, it was also important that I understood subjectivity as Van Manen (1990) defines it.

Subjectivity means that we are strong in our orientation to the object of study in a unique and personal way - while avoiding the danger of becoming arbitrary, self-indulgent, or of getting captivated and carried away by our unreflected preconceptions. (p. 20)

As Van Manen implies, objectivity requires the recognition and affirmation of the researcher's own experience, as well as the experience of others. In phenomenological research it is often a problem that the researcher knows too much about the phenomenon under study rather than too little, and the challenge is to suspend that knowledge. By interrogating and acknowledging our beliefs, assumptions and preconceptions, and making them explicit, in our awareness of them we are much more likely to be successful in
neutralizing their influence than if we were to simply attempt to ignore what we know (Colaizzi, 1978, Guba & Lincoln, 1981, Van Manen, 1990). I made various procedural decisions and included specific strategies in the research design in order to strengthen credibility. In addition, I examined and articulated my biases and my conception of disability. Throughout the study I attempted to maintain a high level of self-awareness by reflecting frequently on the research process, discussing it with others and keeping note of any concerns, insights and ideas that arose.

**Researcher Bias**

My awareness of my biases became heightened as I reviewed the literature and found that it was not reflective of my experience of living with spinal cord injury. It quickly became clear that my view of spinal cord injury did not correspond to the view held by the majority of researchers. My biases, then, are rooted in my experience, and were highlighted by the degree of resonance I found between it and the research.

The term adjustment was problematic in that it lacked definition, not only in the research, but it soon became apparent to me that I, too, was not clear about what I understood its meaning to be. From my experience I believed that adjustment was not a measurable state that one either achieved or failed to achieve. During rehabilitation I was told that the normal adjustment period for spinal cord injury was two years. The fact that adjustment was supposed to occur within a set time frame implied that it was a state, or at least something finite, that either was or was not achieved. Two years after onset of my disability, I did not feel as though I had reached a state that I recognized as
"being adjusted", and in the years that followed I was able to reach goals I had not even contemplated in the first two years. My experience continues to be characterized by new achievements and at the same time, there are still things that I find it difficult to imagine myself doing.

Adjustment is a heavily value-laden word, which also proved to be problematic for me. Success or failure is measured according to how well an individual meets an externally imposed criteria for adjustment within a set time frame. The criteria reflect the values of the evaluator, they are measured without consideration being given to any of the complexities of life that may affect them, and they do not recognize an individual's personal style and preferred lifestyle. What is being assessed is the evaluator's idea of adjustment, which may be quite different from that of the person being evaluated, in terms of criteria and/or time frame. In order to minimize the imposition of my values as I proceeded with the study, I adopted the literal definition of adjustment as "a correction or modification to reflect actual conditions" (Woolf, et al., 1981, p. 15). When a person sustains a debilitating spinal cord injury, a change in the physical body occurs, and possibly, intrapsychic change also takes place. Due to this change many preinjury modes of interaction between person and environment become problematic or completely unfeasible. They must, therefore, be amended to reflect the new conditions. When changes of this nature occur, whether they be physical or psychological, adjustment is being made. Based both on this literal understanding of adjustment and my experience, I arrived at a clear personal conceptualization of adjustment as an individual, ongoing response to change.
The changes in person/environment relationship that are brought about by spinal cord injury create particular difficulties. Typically, adjustments are made in the context of relationship with the external environment. Ordinarily, an individual makes changes to accommodate changes in the environment, but spinal cord injured persons find themselves changed while the environment has remained the same. They very suddenly no longer "fit" into the environment, most obviously physically, and more subtly socially, and many options that are available in and from the environment for other types of adjustments are often not available simply because they cannot be accessed. Through their experience, however, spinal cord injured persons will inevitably encounter both facilitators of change and obstacles to it. Adjustment will be made according to practical viability, available resources, and the person's response to their experience.

Another bias I was aware of when I began this study is a direct product of my experience. I believe the rehabilitation system does not adequately prepare individuals with spinal cord injury for life in the community and is not a helpful resource after discharge. During the years following rehabilitation, important resources to me were friends and acquaintances with disabilities who had gone through the system and were living in the community. It was to this "network of experience" that I looked as I navigated my own experience. Leaving rehabilitation and entering the community was an abrupt passage from one vastly different environment to another, and there was very little to draw on from the rehabilitation experience that was helpful in any kind of substantial way. Rehabilitation was very strongly focused on
the physical, with little or no attention being given to psychosocial and vocational concerns. There was no follow-up from the rehabilitation system post-discharge and I did not maintain any contact after leaving, turning my attention instead to my peers and other supports available in the community.

Researcher's Conceptualization of Disability

Further biases that have grown out of my experience were revealed in examining my conceptualization of disability as a phenomenon defined by physiology, society and meaning, which I described in Chapter 1. In general, people with disabilities are perceived by society-at-large as a minority group which, by virtue of that status, is separated to some degree from mainstream society. Particularly in the past two decades, consciousness of barriers that have served to keep people who have a disability marginalized has been steadily increasing. As a result, the physical environment has become more accessible and, in this way, society has become more open to people who have a disability. Attitudinal barriers have also been overcome to some extent, but continue to be reinforced by an underlying assumption that people who have a disability are members of a homogenous group that is, overall, less capable, and who, instead of being contributors to society must be supported by it. This perhaps arises from lack of education and generalizing of the imagined implications of the immediately obvious physical limitations. It is the mutual responsibility of people who have a disability and people who do not to further knowledge that will facilitate the removal of barriers and, ultimately, the creation of a fully integrated society.
Procedure

Participant Selection and Recruitment

Ten participants were recruited with assistance from the B.C. Paraplegic Association (BCPA) and through mutual contacts. In order to be eligible to take part in the study participants were required to have become spinal cord injured as a result of traumatic injury and to have no impairment in terms of cognitive function. They were required to be at least 19 years of age and to have been discharged from their initial rehabilitation a minimum of two years prior to the date of their interviews. This was to ensure participants had at least had time to gain a certain degree of life experience, both in general, and since time of injury. Lastly, they had to be in general good health.

I was aware from the outset of this research that I held a general assumption that to some extent my experience would be the experience of the participants, and theirs mine. I was conscious that my insider's perspective and my feelings about my experience might interfere with my ability to let the participants' stories unfold without being altered, no matter how subtly, by my biases. Although phenomenology encourages interaction between researcher and participants, it was necessary for me to maintain a certain distance from participants to enable me to keep our experiences distinct, and thus, reduce the threat of introduction of bias. To this end, I made a decision to recruit only participants with whom I had no personal relationship. One participant was an acquaintance, and one other I had known for a brief two month period in rehabilitation, 13 years prior to our interview. In both cases, I had no knowledge of their personal lives. The remaining participants were all previously unknown to me.
The selection criteria was given to a BCPA liaison and copies of a letter of introduction explaining the study (Appendix A) were supplied for mailing to appropriate members. Two people contacted me in response to the letter and after discussing any questions or concerns they had, interviews were scheduled. Introductory letters for the other participants were not sent until they had been given a verbal overview of the study by our mutual contact and I had followed up by telephone, having been given permission to do so. After speaking with me about the study, these prospective participants were told they would be receiving a letter outlining the study in detail (Appendix B) and were asked to contact me after they had had an opportunity to read it, should they still be interested. Whether or not informants speak with a vested interest about their experience is a factor that can influence the quality of phenomenological research and so it was important to me that the participants had a sincere interest in taking part in the study. Recruiting in this somewhat drawn out fashion was a useful screening strategy and, in fact, three participants who had initially expressed interest did not follow up on the letter.

The Sample

The sample of two women and eight men is representative of the proportion of 82% males and 18% females in the spinal cord injured population (Trieschmann, 1988). At the time of the interviews the youngest participant was 26 years old and the oldest was 52. All others ranged in age from 35 to 44. All participants had been injured for 11 years or more, except for one who had been injured for 5 years. Six of the participants had been injured very long term, with the number of years since injury ranging from 19 to 25. All were living
independently in the community at the time of interview and had been for 10 years or more since injury, with the exception of one participant who had lived 3 years in the community. Four participants were employed full-time, two were self employed, one was enrolled in full-time studies and two were involved in volunteer work. All levels of quadriplegia were represented in the sample, from C2/3 to C7/8. This refers to the level of injury. The spinal cord is encased in the vertebral column which consists of 8 cervical vertebrae in the neck, and 12 thoracic, 4 lumbar and 2 sacral vertebrae in the back. Injury to the spinal cord is referred to in terms of where on the vertebral column injury occurred. Thus, C2/3 means the second and third cervical vertebrae, and the part of the spinal cord encased in it, were damaged. Depending on the extent of damage, injury to the cervical area usually involves all four limbs, and it results in quadriplegia. Damage below the cervical area involves the trunk and legs, and it results in paraplegia.

The Interviews

I interviewed participants in their homes, with the exception of two who chose to speak with me at their places of work. They all set aside ample time to be interviewed, and apart from occasional incoming phone calls, there were no interruptions. Their communication during the interview was genuine and thoughtful, and did not seem skewed toward either the positive or the negative. Prior to commencing the interview all participants read and signed a consent form (Appendix C) which, in accordance with ethical guidelines, included notification that they were free to withdraw from the study at any time. Participants were told completion of the Participant
Information form (Appendix D) was voluntary, and all agreed to provide the information requested. Each interview was audiotaped and lasted 1 1/2 to 2 hours. The data collection continued for 10 months due to the researcher's heavy work commitments and difficulty finding suitable participants. As interviews were completed they were transcribed verbatim either by myself or a hired typist. I then summarized each one and mailed the summaries to participants to be reviewed for gaps and overall accuracy. Follow-up was done by telephone rather than in person as, in general, there were few alterations and no substantial additions. During the follow-up, participants were also asked to approve the pseudonym I had chosen for them. A second interview lasting 45 minutes was conducted with one participant due to mechanical failure of the recording equipment in the first half of the initial interview.

To minimize my influence and maximize the opportunity for participants to talk about what was important to them about their experiences with as few constraints as possible, I chose not to develop a schedule of interview questions as it would, to some extent, have been shaped by my assumptions about what was of importance. Conducting interviews without following a set of predetermined questions is often referred to as using an unstructured interviewing format. As Hammersley and Atkinson (1995) point out however, "all interviews, like any other social interaction, are structured by both researcher and informant" (p. 151-152). The important distinction, they suggest, is between the use of standardized or reflexive questioning. The style of questioning I used in this study was reflexive in that questions were shaped by the situation and participants'
responses to non-directive questions intended as triggers to stimulate them to talk about their experiences. Non-directive questions are open-ended, and in using them the aim is "to minimize, as far as possible, the influence of the researcher on what is said, and thus to facilitate the open expression of the informant's perspective on the world" (Hammersley, & Atkinson, 1995, p. 129). My choice of using non-directive questioning allowed me to elicit what participants wanted to bring forth about certain times in their experiences, and to keep on track with their unique experiences by following their leads and posing further questions based on what had previously been said.

Whilst I did not enter the interviews with a list of exact questions to be asked, I did have a clear idea of the two main areas to be covered; namely the experience of living with spinal cord injury and the meaning of adjustment. Participants' experiences are always more complex than can ever be captured and so researchers are forced "to study only aspects of any lived situation" (Giorgi, 1975b, p. 99). I oriented participants to their experiences by bringing the focus to specific parts of it, such as acute care, rehabilitation and community living and asked them to talk about what they thought, did and felt at those times. Upon meeting participants, a few minutes were spent talking informally, and the consent form and participant information form were completed. After answering any questions participants had, and briefly outlining the study and the interview format, I began by asking them to tell me about their experience, starting from the time they were injured. I elicited more and more detail about their experiences and the meaning it held for them by continuing to ask
open-ended, probing questions in response to the information they brought forth.

A flexible approach was taken to the interviews, and participants would often return to earlier points made and expand on them further, either of their own inclination, or at my request if clarification of ambiguity or more detail was necessary. Even with a flexible, non-directive interviewing style "some structuring is necessary in terms of what is and is not relevant" (Hammersley, & Atkinson, 1995, p. 153). Active listening skills are of utmost importance in this style of interview, in that the information communicated must be accurately assessed in terms of relevance to the research focus and how it reflects the interview situation. All the participants showed signs of nervousness to some degree, and several commented that they had never before told their story to anyone. Relying on my training as a counsellor, I attempted to assess and respect participants' comfort level throughout the interview, to keep pace with it and honor their boundaries. For most, their anxiety dissipated 10 to 20 minutes after beginning and they became more relaxed and spoke more openly as the interview progressed. Interestingly, all participants were very sure about when they had reached the end of their stories, and none had anything further to add when given the opportunity at the close of our meeting.

Only when participants indicated they were finished and had nothing more they wanted to say about their experiences were they asked what the meaning of adjustment was to them. This was done to avoid the possibility of their concentration being diverted from relating their experience to how they would define adjustment, and their
connection to their experience being disturbed. Participants were asked what the meaning of adjustment was to them, and for many, this was a difficult question to answer. Many asked me for clarification about what I meant by adjustment. I responded to this by telling them that the research question arose from my finding that no clear definition of adjustment existed in the literature on spinal cord injury, and I reassured them that there was no correct or incorrect answer. I reiterated that I was interested in their thoughts about adjustment, whatever those happened to be. Again, I probed and asked for expansion as they expressed and explored their ideas.

Two deviations from the planned interview format had occurred naturally by the third interview, and are an indication of the flexibility inherent in the style of interviewing. Anticipating that some participants may have difficulty telling their stories, I had planned to use the Life Line (Appendix E) as a tool to help them in this regard. Most often used as a counselling intervention, the Life Line helps people "review their life histories up to the present and to become more aware of their values and needs and of factors that have contributed to their development and current status" (Goldman, 1992, p. 617). Individuals using the Life Line identify significant life events according to when in their lives they occurred and how positive or negative they were, rated on a scale from -10 to +10. I attempted to use this in the first two interviews but, rather than help participants access their recollections, it had the effect of distracting them and pulling them out of their experience as they became more concerned with unimportant "clerical" details such as their exact age when an event occurred. Introducing the Life Line disrupted the natural flow of
their stories which became more a disjointed piecing together of events. Subsequently, participants were told the Life Line was available if needed. It was not necessary to use it, however, as participants had no difficulty speaking about their experience, aside from some initial apprehension which I expected and considered natural for anyone telling their personal experience to a stranger. Upon concluding, half of the participants spontaneously commented that they had found doing the interview to be "cathartic", "good", or "helpful".

Originally the three questions posed by this research were conceived of as separate and were to be asked in succession. As the interviewing proceeded, the second question, "What was helpful in the experience and what hindered?", quickly and naturally evolved into another means of orienting participants to their experience, and was used as such for every interview. Due to the wide scope of the first research question, "What is living with a spinal cord injury like?", it was helpful to participants to be oriented to a certain time and to have the additional focus of what helped and hindered as they talked about their experiences. Phenomenology is a holistic method intended to capture a whole experience, and due to my shortsightedness and lack of appreciation of the fact that what helped and hindered was an integral part of the experience woven throughout the whole, I did not realize that asking about it in a separate question was not congruent with the method. That the method was adhered to, however, is attested to by the ease with which this inconsistency was resolved. As participants spoke about their experiences during their interviews they were asked at least twice about what had been helpful and what had
not, and what the high and low points had been. These aspects of their experience are sufficiently broad and, even though they establish the parameters of the study, they are not significantly constraining and do not unduly restrict participants expression.

It was also very important that I maintained a high level of self-awareness during the interviews since I, too, often felt apprehensive, especially upon meeting a new participant. As well, many of the participants' experiences were reminiscent of my own and I needed to safeguard against any inclinations I may have had to direct participants away from material which triggered my discomfort. To this end, my thesis supervisor read half of the interviews to check for consistency in interviewing style and format, and for evidence of the participant being led by my biases. Rather than regular journal writing, the style of self-monitoring that worked well for me was to spend time reflecting on the interviews immediately after completing each one, as well as when I listened to them again as I transcribed them or checked the transcriptions done by the typists. I noted down any concerns I had and sought feedback from colleagues and my thesis supervisor. On two occasions I did become aware during the interview that the questioning was being motivated by my interests, and not surprisingly, it quickly became confusing and broke down because it had no significance or meaning in the participant's experience. During the interviews I reflected, clarified and summarized participants' stories as they were told which helped ensure we were understanding each other accurately. Occasionally, when participants were speaking about their experience they asked me if mine was similar, thus shifting the focus of the interview onto me. In order to ensure that it
proceeded in a coherent manner and to keep it centered around the research questions, again I consciously preserved a distinct boundary between myself and the participants and answered such queries as briefly as possible before drawing their attention back to their experience.

**Data Analysis**

The objective of data analysis in phenomenological research is to describe the structure, or essence, of the phenomenon under study as it presents itself. Valle and King (1978) define structure as "the commonality running through the many diverse appearances of the phenomenon" (p. 16-17). "Structure is made present to us as meaning" (Valle, & King, 1978, p. 17) and therefore, if data analysis is carried out successfully, we will have understanding of the meaning of the phenomenon. Giorgi (1975a) summarizes the task of the researcher as letting

> the world of the describer, or more concretely, the situation as it exists for the subject, reveal itself through the description in an unbiased way. Thus it is the meaning of the situation as it exists for the subject that descriptions yield. (p. 74)

In qualitative research, data analysis and data collection are done, to some extent at least, concurrently. They can be done completely simultaneously with both being completed at the same time, or data can be collected for the most part before formal analysis begins. In the latter case, some analysis is taking place throughout data collection by virtue of the researcher's reflections about the information being gathered (Bogdan & Biklen, 1982). I chose to focus on data analysis mainly after the data had been collected, although I
did take note of similarities and differences as they became evident during the interviewing and transcribing processes. As I have pointed out, the experience of living with spinal cord injury is not well understood. This study is, therefore, exploratory at the most fundamental level in that its purpose is to "begin at the beginning" and describe the experience. My aim was to allow each participant to recount their experience without being steered in a particular direction, either by my biases or by reformulating the line of questioning according to emerging insights from other participant's experiences. I chose to limit the depth of exploration and stayed within the structure created by the focal points previously identified, keeping with the basic research questions for all participants. It seems appropriate to explore certain aspects of living with spinal cord injury more deeply once the research has established a greater understanding of the whole experience. Time constraints and limited resources were also important considerations in making the choice to keep the design fairly stable.

Data analysis for this study was based on procedures presented by Giorgi (1975a, b) and Colaizzi (1978). The process consisted of funneling the information contained in all the interviews down into distinct thematic categories. After follow-up had been done with each participant on the summarized interviews, and accuracy of content had been confirmed, each interview was read repeatedly as many times as was necessary to get a sense of it as a whole. I then highlighted the "natural meaning units" (Giorgi, 1975b, p. 87). A meaning unit is "a part of the description whose phrases require each other to stand as a distinguishable moment" (Wertz, 1985, p. 165). Copies of two
interviews were given to a colleague familiar with the study who was asked to identify meaning units. Comparison of what we had each identified showed 80% agreement for both interviews. Differences arose from her identifying factual information to which the participant attached little or no meaning and, as well, I had identified some statements because of their commonality with those of other participants, although they may not have appeared to be significant on their own. This peer examination (Krefting, 1991) was valuable in that it confirmed my recognition of certain themes running through the interviews and some new insights emerged from my colleague's interpretation of certain parts of the interviews.

The thematic categorization of the data collected involved many, many readings of the meaning units. They were read at least twice with every sorting, amalgamation, and peer review in an attempt to ensure goodness of fit. Each individual interview was first broken down and its meaning units sorted into 12 rudimentary categories that had become evident during the study thus far. The meaning units from all 10 interviews were then amalgamated category by category. I began to look at the information category by category, rather than interview by interview, and as is common in qualitative research, the information became more divergent and the 12 categories were sorted into 19, under four main headings. These were then subjected to a peer examination which resulted in the recognition of the need for more precise description and labeling of categories, as well as the merging together of some that were indistinct. This resulted in a reduction to 15 categories under the four headings. These were subjected to a second peer review by a colleague who was asked to
match category titles to pregrouped meaning statements, which produced a 100% accuracy rate. She was also asked to place individual unidentified meaning units into the correct categories, which was done with 88% accuracy. As a result of this peer review, one more category was deleted, leaving a final total of 14 under four headings (Appendix F). One of these is a category entitled The Critical Turning Point. It was not included in the peer review due to the difficulty of identification without knowledge of the participant's full experience.

Chapter Summary

This chapter began with a presentation of the rationale for choosing phenomenology to investigate the experience of living with spinal cord injury. This importance of selecting a method that best answers the research questions posed, and is in keeping with the researcher's personal philosophy and way of seeing the world was discussed. Phenomenology was shown to be congruent with my values and philosophy and, unlike quantitative design, it is expansive rather than restrictive and affords much greater opportunity to gain insight into spinal cord injury as a complex life experience. It accesses the experience particularly well in that it presents the participants' perspectives and calls for the researcher's influence to be minimal, both in the collection and analysis of data. As well as including a statement of my biases, my definition of adjustment, and my conceptualization of disability in a discussion of the issue of credibility of research, the steps I took to maintain objectivity were outlined in the description of the procedure I followed in carrying out the study. The data collection and analysis processes were described in detail.
CHAPTER 4
RESULTS
Overview

The results of this study are presented in two sections. The first one puts forth the data collected in response to the question "What is the experience of living with spinal cord injury like?", and includes data relating to what was helpful and what hindered. The second section outlines the information participants conveyed in response to the question "What is the meaning of adjustment?". These are two separate research questions, and in order to keep them distinct, they were asked in succession in the interviews and then analyzed separately. The results pertaining to each are presented accordingly, in two discrete sections. They are introduced and summarized as they are put forward.

The Experience of Living With Spinal Cord Injury

The experiences of the participants in this study are grouped into 14 categories of common experience under four main headings. Each category identifies experience and related meaning that was shared by a minimum of 70% of participants, with the exception of one category in which only six participants expressed similar experience. This was included in that it contributed to a broader understanding of how self-identity was affected by the experience. The degree to which a category was spoken about was not considered the sole indicator of significance. The number of participants identifying a category, regardless of how much they said about it, was deemed to indicate significance as well. As such, some categories contain relatively little information, but, even so, are important in that they add to a more
comprehensive understanding of the experience of living with spinal cord injury. How much participants spoke about certain aspects of their experience may be reflective of length of time since injury, and their current life activity and lifestyle having greater relevance to them than past times. The main headings, entitled Phases of the Experience, Navigating the Experience, Self-Identity, and Support refer to four main aspects of the experience which are connected and, as would be expected given the holistic focus of the research method, interweave as participants' experiences develop over time. The specifics of the development and the time-line involved were found to be idiosyncratic to each participant.

Phases of the Experience

The categories under this heading describe certain points in the experience that participants' progressed through, as illustrated in Figure 1. They do not relate to passing through stages defined by emotional states and responses, although participants did speak about the emotions they experienced at these points of passage, as indicated in the figure. Five categories were identified, and are described as follows. The bracketed percentages indicate the percentage of participants who experienced the progression as it is illustrated in Figure 1.

Disorientation, (90%)

Immediately following injury and, depending on the person, for some time during the acute care period, participants described a frightening sense of disorientation characterized by overall confusion, a lack of understanding about their injury and its implications, and a sense of an unstable and unpredictable future. William had no idea
Figure 1. Common points of passage in the experience of living with spinal cord injury and fluctuation of emotional state.

PHASES OF THE EXPERIENCE
what was wrong with him when he was injured, and kept trying to stand up. "In my mind," he says, "all I wanted to do [was] relax and stand up and go home. That's it, it's time to go....When you're a young kid you're active and you don't know what's happening...I just thought I'd be okay." Steven, too, clearly did not understand his situation. He says, "I couldn't figure out what had happened. Why can't I feel anything? Why? People told me you're paralyzed. What is paralysis? You know, explain to me what paralysis is." Michael experienced a similar lack of understanding. When the doctor told him he was paralyzed and would never walk again, "that doesn't really sink in right away", he says. Patrick didn't realize the implications of his injury either. He remembers his parents commenting on how embarrassed and sheepish he looked when they saw him in the hospital only hours after he was hurt.

I looked as if I'd done something really stupid, which in fact I had, but I clearly didn't realize the gravity of it and I guess I hoped that it was, you know, more of a temporary thing and that it would get better, and I don't really remember at what point I did realize what I'd done exactly and how permanent it was likely to be.

Dan felt extremely confused when he woke up in the hospital. "It was scary. Didn't know what the hell was going on", he says, and Thomas remembers watching an event on television in the hospital and thinking "hey, I got tickets for this, how come I'm not there?" He didn't realize where he was or what had happened. Susan's general sense of confusion about the time in acute care comes across in the way she speaks about it.
Um, what had happened? I don't know. Maybe it was the Morphine or I'm not really sure what it was but I don't ever remember a moment where I was told I wasn't going to be walking again. It just kind of all flowed together and I don't know. Maybe I just knew it somehow.

The extent to which Bob's world was turned upside down by his injury comes across quite powerfully in his words. "In the middle of the night", he says, "you're crying like where am I? Who am I? What's going to happen?" Similar to Bob, a contributing factor in Michael's and Thomas' sense of confusion was their inability to envision what the future might look like. "The whole thing was like a nightmare," Michael says of his experience, "and I didn't know where it was going to end." "I really started getting scared of the future," Thomas says..."I didn't know if I was capable of being married, obtaining full-time employment, going to school, being out with my friends, just carrying on."

At the time when participants found it difficult or impossible to picture what the future might look like for them, three commented that they also found themselves contemplating suicide. As Thomas intimated, "at some points at [the hospital], you really thought twice if you really wanted to be part of this world anymore." Still in hospital six months after his accident, Michael says, "I decided I didn't want to live like this and I was thinking of different ways of suicide." For him, there were no apparent alternatives to living "like this", which, at that particular time, meant being completely dependent on others. Dan, lying in intensive care unable to move at all, says he just thought life was over. "Your first thoughts are well, let's get this over with, let's
just bite the dust, what the heck am I doing here?...I wanted to just get this over with...Yeah, they told me I'd never move anything so, not even my arms." Patrick had a brief suicidal episode but not until after he had left rehabilitation and moved to the community. Similar to the others though, it was the possibility of having no alternative to a future of dependence that provoked it. Staying with a friend in an inaccessible apartment, he found himself having to be dependent on him and he had the realization

that...without the right place to live and the right stuff I am really, you know, not independent at all...I think that's part of what that episode was about, was realizing that, you know, that I am potentially quite dependent, and so maybe it was just a little bit scary for a while.

With that future vision in his mind he says he remembered "saying amidst the tears that I just wasn't sure I wanted to live this life."

During this period of disorientation it is almost as if participants find themselves suddenly displaced into a completely foreign world in which nothing from their familiar world is recognizable. As Steven says, "everything, everyday, is different" and, in fact, six of the participants made references to having to start their lives all over again after their injury. Ann talked about her whole life having been swept away when she was injured and her life afterward as being new. William says "you start again from scratch, you know." Patrick described it as "like growing up all over again" and Dan remembers his doctor telling him he would have to start life again. "And he was right," he says.
Rehabilitation. (70%)

The general rehabilitation experience was spoken of in positive terms, whether participants referred to the environment, or to themselves becoming more positive as a result of being there. Four participants conveyed mixed feelings about how they experienced rehabilitation. For Steven going through rehabilitation was one of the most humiliating experiences of his life but, he says, "looking back on it, it was the best thing that ever happened...It's the best place to be." Dan found it hard, but he says "I think rehabilitation was the best thing I did...It just showed me that I was starting to do things, and even if they were small things, it was something - not totally hopeless." "The rehabilitation centre was very helpful while you were there," Bob explains. "They maximize, they pushed you to do as much as you can to get as strong as you can in a year." Patrick considered what he was going to learn in rehabilitation as "probably the most important bit of education" of his life and to him, the rehabilitation centre he was at was "a good place to be." He was "so preoccupied with that learning process and absorbing all [the] new information," he says "that I didn't have time to get too depressed or feel too sorry for myself." Unlike Patrick, when Michael saw that he was beginning to make some progress in rehabilitation he still experienced the depression that had begun in acute care, but he "started to get a little more positive."

Entering the community. (90%)

Participants' recollections of moving from rehabilitation into the community were, to varying degrees, negative in that they found themselves unprepared for community living, which contrasted sharply with life in the rehabilitation centre. Feelings of fear and
isolation were common at this time. Bob and Thomas describe just how stark the contrast was for them. Bob talked about having some anxiety leaving the rehabilitation centre because, as he explains,

you're coddled there and there's many nurses and physios...You get lots of praise and positive feedback and someone's always around caring, and then you get out in the world and that stops like immediately. So it's like, wow! Where are all these people telling me I'm wonderful and encouraging me to exercise and keep going? So that stops abruptly.

Thomas also talked about suddenly finding himself on his own when he moved into the community. He no longer had his physio "holding [his] hand" or his other friends in chairs to be around. This was definitely a low point for him. "I was never depressed until I left rehab," he says, "and that's when I started turning to drugs for support, and alcohol."

He goes on to describe the differences between the physical environments of the two settings.

At the rehab centre everything's wheelchair accessible, so you go, well, life isn't that bad. Once I moved to the community I realized that there's hills, that there's no curb cut-outs or curb cut-outs are too hard, bathrooms that you can't get in and out of, stores that you can't get down the aisles...The environment [in rehab] is so protected, everything is wheelchair friendly...but outside is where real life kicks in and then you find some problems.

When Patrick left rehabilitation, he likened it to leaving the womb. "I was so protected. I remember having that sensation of being protected and basically having my needs taken care of by everybody else at the rehab centre...Just sort of cutting the umbilical cord or whatever was
scary." The fear associated with moving from the security of the rehabilitation centre out into the community can also be discerned from the way Dan and Greg described their experience of it. Dan moved into a group home in an area he was unfamiliar with, where he didn't know anybody and felt isolated. He says,

If you stay [in rehab] long enough you get institutionalized; you rely on that safety net. If anything happens they're right there to help you. It's harder and harder to go out. It was hard to come to the group home...Boy, that was like going from, I guess, acute care to rehab, another big moment in your life. Oh no.

Greg remembers being excited to be leaving rehab but things clearly took a turn for the worse when he was discharged and moved into a housing complex for people with disabilities. Once he was there, he found himself feeling alone and frightened.

Rehab and the hospitals, you know, they have nurses to look after you and it's a comforting place...so when I moved into the housing complex I felt a bit uncomfortable there, a bit on my own and isolated and a little depressed...I would have to say, things got worse from there. It was difficult for me to cope 'cause I was on my own, and so I had emotional problems adjusting. 'Cause here I was faced with reality. Oh no. I'm on my own. What am I going to do?

In speaking with her physiotherapist about the situation she was going to be returning to when she went back to her rural home after rehabilitation, Susan had an idea of what she needed to work at to ensure that she could deal with being there. "However," she says, "I think that dealing [with it] was more in my mind than physically, because I had no idea what that involved in terms of how I was going
to get around." After learning to do transfers and practicing them "a total of two or three times" she says, "it was up to me to go home and figure it out." Being back at home was not easy.

Oh, it was hell. I was really isolated in the country. I spent more time at home where I felt trapped. I didn't have a driver's license, I didn't get around a lot. Plus rehab was short and I was really, really weak. It wasn't fun out there. It didn't do much for my self-esteem, my self-confidence.

For Steven, moving back with his wife and children into an newly built apartment was extremely difficult, both emotionally and physically.

It was horrible. It was the worst thing in the world. We were arguing with each other constantly. We'd just scream at each other and the kids were crying, and, oh Lord, it was like 99° out there and a manual chair and I couldn't push it....To go shopping, she didn't want to leave me at home and I didn't want to stay home alone, kids were too young, so she'd try and push me on this gravel bloody road 'cause there was no pavement in that new area.

Thomas, Susan, Steven and Bob made reference to the physical difficulties outside the rehab setting, but nine out of the ten participants spoke about the effect the move had on them emotionally. Their descriptions of feelings of fear, anxiety, depression, conflict, isolation and low self-esteem, indicate that they would agree with Michael that "mentally, or emotionally or whatever, you're not prepared at all for the outside world and what it's going to be."

Coasting. (90%)

Coasting refers to a period of limited activity which all but one participant identified as being part of their experience. This occurred
at some point after discharge from rehabilitation, and lasted anywhere from one year to as long as seven years. It was not an aspect of their experience that participants talked about in depth. For Michael and Ann, it was not concurrent with their departure from rehabilitation and entrance into the community or, in Ann's case, admission to an extended care facility where she lived for one year. She then left there and lived in a group home for another year. It was not until she returned to extended care again after the group home experience that she "basically didn't do anything." She says, "I vegged out for, oh, maybe three, four years." Michael had returned to university in the fall following his discharge, where many of his friends were also in attendance. When they all graduated and he found himself alone, he discontinued his studies and became withdrawn. He took correspondence courses and found a seven month employment contract. It wasn't until after that ended that he remembers a period of about three years where he "wasn't really doing anything." For others this period coincided with their return to the community. Susan describes what it was like for her when she was back at home. "I wasn't doing a lot," she says. "Watched a lot of TV and that was about it for probably the first year of my injury." Greg "partied his brains out" like everyone else where he was living. He "drank a lot and didn't do much." Similarly, Steven says, "I didn't go forward or backward, I just partied." For the first five years Dan lived in the group home he "just hid from everybody, didn't want to go out nowhere, never went anywhere, very rare." William, living with his father after rehabilitation, remembers that for seven years there were no friends. "It was just Dad there, and that was it." That this was a time of
inactivity comes across vividly when he says it was like "putting you into jail and staying there."

The critical turning point, (80%)

The critical turning point refers to a low point in the participants' experiences which is followed by a gradual positive escalation. Half of those who spoke about a critical turning point identified the time during which it occurred as the lowest point of their experience. It is associated with high stress, and is characterized by the participant's decision to take control and turn the situation around. The presence of a conscious decision to take action to reverse the negative situation is what distinguishes the critical turning point from other low points participants also experienced as very distressing. The perceived consequences of not taking control were severe and included suicide, mental illness, drug and alcohol addiction, and complete powerlessness. The time at which this turning point occurred was idiosyncratic, happening as early as a year and a half, and as late as ten years after injury. The length of time it lasted was also unique to each individual.

Four years after his injury, Bob went down into a depression "big time". He and his partner, with whom he had been living, ended their relationship and he found himself living truly on his own for the first time since his accident. On top of the emotional toll of ending a relationship, he was "scared to death", finding himself alone and unsure of how he was going to manage. His description of this time has the hallmarks of the critical turning point.
So the feelings were, you know, loneliness was a big part of it, depression, just, 'well, okay, that didn't work, a relationship with an able-bodied girl, so I'm doomed...I'm alone the rest of my life'. Just all the negative thoughts reared their ugly heads and they went unchecked for too long. I just believed all the negative thoughts...After 6 months, or 8 months of negative thinking I pretty much reached the bottom - not quite suicidal, but as close as I want to get - and then I said 'this is enough. You're going to stay like this or I have to do something to change'. Well, I decided to do something and think positive...Through the grace of God and wonderful friends I rebounded and life is pretty good.

Dan "bottomed out" 10 years after his injury when "everything just came crashing". He had spent years fighting through the legal system for a settlement from parties involved in his accident, and when he lost the case, he also saw himself losing the independence he believed it would have brought him. "That was my last hope [of] being able to support myself," he says. "Maybe get out of the group home...My only way out was with the lawsuit, or at least I thought it was." Dan lost his relationship, his home and his employment after his accident, and finally the court case. His way of dealing with these losses was to ignore them. "I never dealt with anything. I just put it behind me...I just put it back, didn't deal with it, just kept it down there, made out I was happy". In retrospect, he realized that as a result he got "some pretty big anger down there...and if you keep suppressing it, it comes out eventually or you just get sick. I think that's what got me really sick; just too much emotional stuff down there." After two years of poor health, feeling physically and mentally
drained, all the emotions he had been keeping inside "just came pouring out...That's when I let loose and said that I needed some help. So I got it." Dan had "put everything into winning the court case" and without this last hope to hold onto anymore, he had to "deal with the reality that [he] had to figure something else out." Getting to that realization involved hitting "rock bottom" first, but with the help of a counsellor, he saw that there were other ways to get what he wanted. Getting help "turned me right around," he says. "It's been great....Losing the court case, bottoming out, getting back into life", he says, is "probably the best thing that ever happened."

The critical turning point in Ann's experience happened in the extended care facility she had moved back to after finding living in a group home situation untenable. At that time, returning to extended care was the only viable option she was aware of. She was not happy there, where she found the environment depersonalizing, over-regimented and filled with class-hatreds, the residents being at the bottom of the hierarchy. Not long after her return, she was wanting to leave. "From the very first few months, I think I always thought, 'well, maybe two years, maybe five years, maybe eight years, maybe ten years.'" When the unionized staff at the facility went on strike they threatened to keep everybody in bed, and that threat was what finally motivated her to take action. "That was just sort of the last straw", she says. "It got me thinking, you know, I'm not going to take this again....and I went to the [social worker] and I asked him to help me after the strike was over; help me get out of the place." Fortunately, the apartment where she now lives was vacant, and she did not have to wait long.
After living in an inaccessible suite for 7 years with his father, and feeling socially isolated during that time, William moved with him to an accessible apartment in a building where many other people with disabilities lived. "And life started", he says. Although this turning point in William's experience appears positive, it was not entirely so. "Once I moved," he says, "then I started to realize a lot of things. Yes, we could party, we could go out and have a life outside in society; we could go ahead and have a job; we could have a relationship." On the downside, however, suddenly having so many potential opportunities open up to him after years of them being very limited was overwhelming. As he explains,

You move into this complex and this great big reserve is there for you all of a sudden. You don't know what to think. It's like coming into a candy shop...you don't know what to grab...I didn't know what to do. It was just given to me. It was thrown to me, like, here - choose now. I think I'd say that was a low point because I didn't know what the hell to do. It was a lot better than living at my old apartment, 'cause now I have a life. But how am I going to adapt to it?

The move was clearly unsettling for William, and to cope with the enormous change it brought he thought of both the positive and negative options, and decided to choose the positive. "Now which is the better string to pull," he wondered? Is it drugs? No. Booze? No. What is it? So to me it was friendship. Socializing." By making this choice he prevented this low point from dipping even lower, and over time, with "support from all avenues" he did adapt.

Susan's separation, "much as it wasn't fun to deal with" was a critical turning point in her experience.
That was a good, good thing...it was a really good event to happen for me...That's when I felt like I had the opportunity to do things the way I needed to do them instead of trying to please everybody else and not really get on with what I needed to get on with...I had lots of distractions in my life. I didn't have to deal with myself. I had lots of other people to worry about instead. And I did.

I really needed to rely on myself so I started learning how to do things after our separation. I did before...as well, but much more after...when I had my whole life ahead of me....I just went on, you know, I had my whole life that I could do whatever I wanted with. So I did.

Susan's description of this part of her experiences illustrates clearly that although the event associated with the critical turning point is negative or, in William's case, has negative repercussions, the long term effect is positive, allowing the event itself, in retrospect, to be cast in a positive light.

In summary, five phases of living with spinal cord injury representing points of passage in the experience have been described. Disorientation, associated with acute care immediately following injury, involved participants feeling a sense of confusion, both in general, and in particular about their injury and its implications. This was a frightening time for participants when the future seemed extremely unstable and uncertain. From acute care participants moved to rehabilitation which was experienced as a positive step, although some had mixed feelings about it. Entering the community, the next point in the experience, was negative in that participants felt ill-prepared for community life which was vastly different from life in the institutional rehabilitation setting. Not necessarily immediately afterward, but at
some point following discharge from rehabilitation, participants came to a point in their experiences when they went through a period of inactivity, or coasting, the duration of which was unique to each individual. The fifth point participants went through was the critical turning point, which was idiosyncratic both in terms of when, after rehabilitation, it occurred and how long it lasted.

As participants progressed through the phases of the experience it was apparent that they were also engaged in a process of navigating the experience. This process is presented in the following two categories under that heading.

Navigating the Experience

All participants indicated that as they faced the future, not only at the outset of their experience, but as they progressed through it as well, they often found themselves facing the unknown. Michael, Thomas, Bob and Patrick all talked about feelings of anxiety or fear associated with times when they did not know what lay ahead. Thomas says, it was "really frightening.....Everyday was a new experience for me. It was like, whoa! Do I really want to try that today? Can I try that today? Is it possible? Susan too, at one time did not know what was possible. "There was a time there where I really wasn't sure of what I was capable of doing or not [capable of] doing, or how my life would go," she says. Dan says simply, "I didn't know what the hell I could do anymore."

The sense of the unknown was experienced as being both global and specific to a particular event. Michael did not know how things were going to work when he moved back in the community. Even though he had home care arrangements in place when he left
rehabilitation, he says "I was really, really anxious to go home, not knowing what home care really was." As Patrick explains, "there is always the bit of fear of the unknown or things that you don't anticipate and things that you don't really appreciate until you actually live them." Bearing in mind that participants found themselves dealing with the unknown and grappling with a new and foreign world after their injuries, two components were identified which, together, resulted in participants being able to forge through the unknown and make forward movement in their experiences. These were discovering possibility and pursuing possibility.

Participants' movement through their experiences is most obviously apparent in the physical events that take place, such as an increase in physical ability or changes in residence. The two categories under this heading, however, describe, firstly, an interactive process participants engaged in whereby they found affiliation with other people who have a disability, and, secondly, the implementation of a strategy of being open to and pursuing alternatives, both of which were helpful in the discovery and pursuit of possibility. Navigating the experience, then, refers to how participants made their way through their experiences in terms of the underlying social, emotional and cognitive factors involved in participants' discovery and pursuit of possibility.

Finding affiliation.

Nine participants spoke about finding a sense of positive affiliation with other people who have a disability. Thomas, Dan and William discovered this when they came to rehabilitation, but for others, like Susan and Ann, it did not happen until after they had left.
Through this affiliation, participants became aware of possibilities and had the opportunity to learn from the experience of others. It also brought an emotional and social connection with others which impacted how participants felt in themselves. This connection is clear in Dan, Greg and Michael's experiences.

Feeling suicidal in acute care, when Dan came to the rehabilitation centre, he "started hanging out with people that were in the same situation" and his attitude became more positive. "I had lots of friends; we used to go out and do things." Although the reason wasn't completely clear to him, being out in public didn't bother him then "because I guess I was out with other people in wheelchairs, maybe that was it." Greg felt a similar affiliation with his teammates when he got involved with wheelchair sports.

You get to be with other people in chairs and sort of feel normal....Everyone wants to fit in with everyone else so it's great when you're doing the sport or doing something together with other people in chairs. The comradeship was great. Yeah, it was pretty good.

Michael talks about his first paid employment after his injury, working full-time on a project with other people with disabilities when he had returned to the community..

I found that to be really challenging, but really beneficial and good for my self-esteem because here I was with other people with disabilities; I didn't want to be, like, packing around with people with disabilities, you know, like, herding around, because I didn't want to be seen with a group of people with disabilities. But I didn't mind this group....Just the whole interaction, and you were able to tell your experiences.
The sense of social connection, or the absence of it, was also evident when participants spoke about a lack of affiliation or its potential loss. Michael and another person who had a spinal cord injury had been going through the acute care experience together, and when she left for rehabilitation ahead of him, he "felt left behind." When the three people with disabilities Thomas socialized with were all starting new employment, he realized he "was going to be left alone" and wondered "am I going to be by myself watching TV?" When he had the opportunity to join in the employment project with his friends he says "it just helped me out a great deal to carry on, even though I wasn't falling into a bad rut, but I wanted to be part of that group again. I enjoyed the group that I was hanging out with." When Greg moved into a new housing complex, he found himself feeling lonely. "I didn't like it very much," he says, "cause I was on my own a lot and didn't really know anyone and didn't have very many friends or family. So that was a bit lonely there."

For Susan, a lack of affiliation initially, and finding it later on, greatly affected her experience. In rehabilitation there were only two other people with spinal cord injuries going through when she was there, and there were days when they did not even see each other. She explains her experience.

I didn't have the opportunity to interact with other people that were in the same situation as I was and I think because that didn't happen right away - well, I don't know, but it sure contributed to it - that after I was out of rehab I had a really, really hard time with it....When I started university and I was all of a sudden in a huge group of people that included other people with disabilities, I would pretend somehow in my mind that I didn't have a disability...I don't know how I managed to do that.
While attending school, she took part in a peer counselling program which had an emphasis on self-awareness, and it was there that she found a sense of affiliation.

It was group work and everybody in there used a chair and had a spinal cord injury, so that was really, really good for me...Made a difference, yeah, to see if there were other people around that were all right....In terms of interacting with other people or getting a sense that I was all right even using a chair, it didn't start until I started having contact with other people that used wheelchairs or had some sort of disability.

Unlike Thomas and William, who talked about benefiting from congenial competition with their peers in rehabilitation, Ann had a high injury resulting in a very limited level of physical function and she says, "I knew I could never compete." In the rehabilitation centre, it was the aloneness she remembered and after leaving, she alludes to the continuing absence of affiliation with other people who have a disability.

I wish there had been someone around who could give me some kind of a clue about what it was like to be out in a wheelchair the very first few times...I just really wish that someone had shown me what it was like.

Ann did not talk about experiencing a positive affiliation with other people with disabilities until many, many years after her injury when she became involved with a disability organization. Through her work there she became exposed to the cross-disability movement which was helpful to her. It was then that she realized that "there's a whole lot of people out there that are thinking people, and they want
to make the world a different place." Referring to her colleagues, she says, "I don't think I've ever met a group of people that are so committed to helping each other, and that's a good feeling."

Through their affiliation with other people in a similar situation, participants were able to see possibility. Ann's affiliation with her colleagues showed her that there was a possibility for social change to take place and that it was possible for her to take part in bringing it about. Susan talks about how inspiring it was for her to see Rick Hansen wheeling on his 1986 world tour because "he was just a really good example of a possibility."

It was incredibly inspirational to me...Here he was, and we had a similar life situation, and look what he's just been able to do. Not that I wanted to go wheel around the world, but, gee whiz; there's a good example of somebody surviving and being okay.

When Thomas came to rehabilitation and saw others with disabilities similar to his it was an "eye-opener" to be able to see himself in relation to them. He saw how far other people with his disability had progressed and realized that he was at the "worst bottom end of the bucket" but that he too, would progress and find himself at their level "months down the road." "In due time I knew that it would be better," he says. "So that really helped me out a lot." Being with others in a similar situation and seeing that there was possibility, the fear he had in acute care when he did not know what he would be capable of doing began to retreat to the back of his mind instead of being the first thing he would think about when he woke up each day. When William was in the hospital before he came to rehabilitation, there wasn't another person with a disability similar to his with whom
he could "really see eye to eye". Much like Thomas, when he came to rehab he saw other people with his level of injury and it "opened up his eyes".

Finding affiliation created the opportunity for participants to learn from the experience of others and integrate the possibilities that became evident into their own experience. Susan relocated many years after she was injured and began a new job working for an organization where other people with disabilities were also employed. "Some things I didn't actually figure out until I got out here," she says, "and people kind of looked at me and said 'what?' 'What are you doing?'... 'What do you mean you're still using your sliding transfer board?'" Working where she does, she says, "I just have the benefit of everybody's information and experience to pick and choose from, which has been good, really good for me."

Both Thomas and William entered into friendly competition with their peers in rehabilitation. "It wasn't a level where, you know, 'I'm better than you', 'cause it was competitive, but it was like a team", William explains. "We [did] compete with each other," Thomas says. "We used to help each other out." Being around other people with all different levels of injury gave him the opportunity to see how they did things, and he would build up his own skills from what he saw. The sense of affiliation comes across strongly when both Thomas and Bob talk about learning from those who shared a similar experience. Thomas says,
Asking somebody with the experience over somebody that's walking along in the hospital saying, 'you can do it this way', I would believe a person that's in a wheelchair moreso than a person that's walking, 'cause they've done it....Even though the physios and occupational therapists are...trained individuals in their profession, still seems to sound better from a person that's got a disability. They know where you're coming from...I mean, they've been there, they've done it.

Bob talks about the value of those with experience helping others, which he learned from his own experience.

I mean we are the experts; we've been through it. It's one thing listening to an able-bodied doctor go 'well, it's going to be like this'...As he walks away you're going, 'okay, I'll file that'. But if someone cruises in your room in an electric chair in the same position you are in, or worse or better, you're going to listen.

Greg found it difficult sharing accommodations with the person he lived with after he left rehabilitation. In addition to their personalities being quite different, he says, "[my roommate] wasn't a spinal cord injured person so it was a bit difficult to relate to him because we weren't going through the same problems." Without affiliation with someone whose experience was similar, he did not have the opportunity, as Bob did, to benefit from another's experience. Bob says, "I was fortunate to move into an apartment with a person I could relate to, who was a couple of years my senior as far as being injured two years before I was, so [he] had experience and that really helped." After rehabilitation Dan also moved in with a roommate with whom he had a lot in common, including the fact they both had spinal cord injuries. He talks about how helpful that was for him.
It's good to have somebody else in a wheelchair for the first few years. See that you're not the only one, that they have problems too, and then you have problems. That was good for me. Even if they're a little better than you, it's nice. It helped out a lot....just seeing how they're getting along, they're having the same problems as you, the same emotions, it's great.

Through finding affiliation with others in a similar situation, whether in rehabilitation or later, participants discovered they were not alone and that there were new possibilities and options available to them. This is not to say that without affiliation and having other people who have a spinal cord injury as models, that participants did not progress. Before Ann and Susan found a sense of affiliation for example, they both devoted much energy to exploring options, in terms of living environment in Ann's case, and education and employment in Susan's. Greg "didn't know what he wanted to do" after rehabilitation and tried different employment possibilities, as well as going to school, before he found affiliation through his sports team.

Whether participants spoke about feeling affiliated on a physical, social and emotional level as Greg and Dan did, or, like Bob, spoke mainly about feeling affiliated because of physical similarities, all nine indicated finding affiliation with other people in a similar situation had a positive impact on their experience and facilitated progress. Regardless of whether participants identified possibilities using their creativity, or through their interactions with others, by doing so they demonstrated an openness to options fundamental to the strategy of pursuing options. This strategy is described in the second category of navigating the experience which follows.
Pursuing options.

All participants either described a strategy of pursuing options or demonstrated it through their actions. Underlying this strategy is a general positive attitude of being open to alternative ways of doing things as well as alternative ways of thinking about things. For one participant this attitude has remained constant throughout his experience and pursuing options has consistently been central to it. Three participants demonstrated a definite pattern of actively pursuing options followed by withdrawal, followed again by pursuit. In Michael's case, a pattern of pursuit and withdrawal repeated three times. For all eight participants who experienced a critical turning point, active pursuit of options increased following this phase and no further periods of withdrawal were indicated. This strategy was strikingly clear in participants' descriptions of how they approached mastering specific tasks of daily living, and it was more subtly reflected by the larger life events they described in their stories. Regardless of the context in which it was used, it indicated an attitude of openness to alternatives. Although use of the strategy did appear to fluctuate, for all participants it was a guiding force.

Patrick describes the attitude underlying the strategy as "a willingness or even an inclination to explore different ways of doing things or different ways of thinking about something." Michael describes his openness to alternative ways of thinking about things when he talks about the progress he has made in his experience hinging on being able to look "at things differently; changing your attitude in order to get back on the positive side; looking at things in a positive way rather than maybe you were looking at it in a negative
way before." As Dan's experience attests, negativity is likely to inhibit forward movement. He talks about his switch to a general positive attitude, and clearly now he is open to exploring options.

Well, before my attitude was piss poor, and now it's positive....I'm trying to be as independent as I can be now....People will make suggestions and if I think they're good, I'll act on them. I don't cut them off anymore. Like, I don't say 'well, that's not going to work, I can't do that'. At least I try.

Changes in attitude or thought were actively pursued by Bob when he made a decision to "turn on the positive thinking" to bring himself out of his low at his critical turning point. Thomas also appears to have acted consciously to become a "more likable person" after his injury. "I tried to be more social," he says. "I used to be a little bit of a rebel...and I realized I had to change my attitude." Changes in attitude and ways of thinking about things sometimes occurred much more spontaneously without having been sought. Talking about getting back into a positive state of mind, Michael says,

I don't really think I thought consciously 'okay, I'm going to try to...do things positively.' It was just a day by day different way of going about things or looking at things. I didn't really think about it. It just happened.

Susan and Bob both talked about suddenly finding themselves receptive to hearing comments that presented an alternative point of view which they then adopted. These instances had a positive impact, but rather than indicating a general shift from a negative to a positive way of looking at things, they reflect a change in a specific thought pattern. Attending a conference and hearing a member of the audience
say that having a disability was not all-consuming, but rather it was only one aspect of a person's life, marked a turning point in Susan's experience. Never having thought of it that way, she says, "it made sense to me...It just clicked." She explains further,

I think from the time I was injured and going through rehab...everything is geared to how you do something being a person using a wheelchair and so I know for me a lot of times that was my first thought in absolutely everything I did or thought about...After hearing that statement, it was a different way to think about it...Maybe I don't have to be so concerned about how it's going to work out because I use a wheelchair, but it'll just work out the way it works out.

Bob had an experience similar to Susan's. Feeling depressed one day in rehabilitation, he says, "one of the doctors said the right thing at the right time when I had open ears." When he asked Bob if he was "always happy and had great days and nothing bothered [him]" before his injury, he admitted that, indeed, he had had times when he felt sad or depressed. The doctor suggested then, that perhaps he was just having one of those days again. "So I heard that", Bob says,

and I was probably told that a dozen times before then but it just finally sunk in; so that really helped...I was ready to hear it and [it] just woke me up to the fact that life wasn't perfect before my injury and it's going to be challenging after, so not to freak out the first time I get depressed...'Course I still have bad days and just...put it off to 'well, so does everyone else'. It's not exclusively 'cause I'm in a wheelchair. So things like that were really helpful; little vignettes that people would advise.

William too, experienced a change in the way he had been thinking about where home was for him. Having made an effort
to connect with relatives visiting from his hometown, he was hoping to get some emotional support from them. "I didn't get that support", he says.

When I was coming home, the closer I got, the more I felt at home. So, from the time I was living in my hometown, I always probably had in my mind that was my home, but that is wrong now; that is negative. This is my home.

Ann describes the strategy of pursuing options when she says "through the years I haven't had a lot of 'you can't do such and such anymore'. I've had more of 'well, you can't do such and such anymore, so let's find a way that you can do it; a different way'." William describes it when he says "you gotta go out there and explore for a different lifestyle; a different meaning of life." Bob, Patrick and Thomas describe it when they talk about their approach to finding ways to do physical tasks. Bob's sense of humour comes across as he explains,

Necessity is the mother of invention. So you can't reach something, you think, you don't want to get beat. You don't want the straw at the other end of the table to beat you, so you figure out a way to get that straw; to get whatever to pick something up, and it's like you've just run an Olympic gold medal, run the 100 yard dash for getting some stupid book off the floor because you spend an hour and a half with a coat hanger.

That finding a way to do a task can seem like a monumental task in itself, as Bob suggests, is also something Patrick makes reference to.

It's a matter of developing a knack for something. I mean, you might not be able to do something the first
three hundred times you try, but eventually you figure out a way that you can do it, or a certain angle that you have to be at, or whatever. A lot of trial and error.

Thomas also talks about 'figuring out a way' to achieve tasks, indicating that he, like Bob and Patrick, is open to and actively pursuing options.

[With] time and trial and error, you figure out a way. If you really want to do it, it might look impossible..., but if you put your mind to it, I think there's always a possible way of doing it, one way or another.

By being open to options and actively pursuing them, Thomas discovered he was capable of much more than is to be typically expected for a person with his level of injury. He, Susan and Patrick all pointed out an important aspect of the strategy was not allowing others to define the limits of their capabilities. Thomas explains that,

When people said 'you're a quad, you can't do that', I went out of my way to prove them wrong; to figure out adapted equipment or whatever I might need to do that certain task...I found that the more people told me that I couldn't do things, the more I would try.

Susan had the same reaction.

I have this attitude which has been very helpful to me, which is...anger, I guess....The more somebody told me I wouldn't be able to do something ever again, the more I figured 'Oh yeah? Well watch this.' I'm not sure what it is but it worked well for me....My intent was not to let somebody tell me how my life was going to be because of this [injury], or believe them when they said it. It's helped me out.
"Not necessarily accepting anybody else's word for what's happening or how to deal with things or how to do things" is a part of pushing boundaries and exploring options that Patrick draws attention to as well. He clearly recognizes people's individuality when he goes on to elaborate.

I think it's important for an individual to adapt their own technique or their own ideas about how things need to be for them or how they should do things. So it seems important to me if somebody tells you 'okay, well, this is the way you do it'...not to assume that that's correct.

While a great part of daily life is concerned with carrying out physical tasks and participants devoted a lot of energy to relearning them after their injuries, they also demonstrated an openness to options and pursuit of alternatives in regards to "different lifestyles and meanings of life" as William said. A shift in Steve's attitude and his active pursuit of options is obvious when he describes a time in his experience after his critical turning point. Reflecting back to earlier days, he says,

We'd wake up with a bottle of beer and a joint and a bowl of popcorn. That was it...Then I didn't have a goal; just get up and get pissed...Now I've got a goal in life, which is good...I'm getting on with my life. I'm going to do something with it...I've stopped doing so much partying; I've taken courses; I'm bettering myself and trying to open my own business.

Susan is not only open to new ways of thinking about specific things, as we have seen, she is open to new meanings of life. She says,
I think that when I was injured I saw my dream, my little house in the country and white picket fence and kids dream, shattered. I think that was a big one for me. However, over the years I've discovered that, yes it was just a dream; it wasn't necessarily going to become a reality....I've since come to realize that this is my life and I can make it mean whatever I want to.

Dan, too saw his dreams disappear when he had his accident, and although at the time he took part in this study he did not see any possibility of getting them back, he still had an attitude of openness.

There was lots of dreams I had before this. Kids, family, working, all that; and it's gone; it's history. That's hard. I always wanted a big family...and that's never going to be a reality....It's not an easy thing to go through, breaking your neck, and your whole world changes in just that fraction of a second...But there's lots to live for and lots of new things to experience. [It's] still good.

Examples of participants' openness to and pursuit of alternatives are plentiful in their stories. Feeling like she had been "thrown on a garbage heap" when she first went to extended care, Ann's first year there was "one long fight to get out", ending in success. Living at home, Michael knew he was "on [his] mother's case a lot" and that it was not good for either one of them, so he "took the plunge" and moved out. Not wanting to live with his parents, after convincing them he would be all right, Bob moved back to the place he had been living before his accident, "where his heart was." Medical problems secondary to his injury prevent Greg from being able to have a 9 to 5 job, "so I have to
just do what I can," he says. Being open to other options he started a home-based business.

Only time can reveal the course of an individual's experience and the stability of each participant's attitude of openness to options. Their pursuit of options cannot, therefore, be spoken of in absolute terms as long as the experience continues. For five participants, however, ten or more years had passed since they had increased their active pursuit of options after they experienced their critical turning point, and, as mentioned, no further periods of withdrawal ensued. Thomas suggests that pursuing options is a strategy that is firmly integrated into his experience when he says "even things I thought were impossible three years ago, once in a while I'll take a shot at [them] again." Realizing that openness to options and pursuing options may not be absolutely stable characteristics of his experience even though they have been constant thus far, Patrick says, "I would hope that that's actually ongoing....I like the idea of continually refining and continually learning."

Self-Identity

Participants did not speak in detail about the impact their injuries had on self-identity. Half of the sample indicated that their perceptions of self were initially disrupted by their disabilities, either because of changes in the way they experienced themselves physically, or due to the effects of disability on the social self. Participants indicated their connection to core aspects of themselves was preserved, however, and it was evident that after the initial disruption, they gradually regained a stable sense of identity as they worked their way through their experiences.
The five categories which follow were identified as having relevance to the theme of self-identity. They do not describe steps in a process that explain how participants went about restabilizing their identities. Rather, they present participants' descriptions of how they experienced themselves at various times after they were injured. These descriptions indicate a pattern of change wherein destabilized identity again became stabilized, suggesting participants were engaged in a process of regaining a stable identity as they went through the process of navigating their experience. The pattern of change was dependent upon participants' active involvement in their experiences. Four of the categories outline the different ways participants experienced themselves and demonstrate that change was facilitated by their being active. The fifth category describes an interactive social phenomenon which influenced the way participants experienced themselves. It was evident that how participants perceived they were seen by others influenced their sense of self. Social interactions, relationships and situations in which participants perceived either a positive or negative reflection of themselves from another are described in this category.

Destabilization of identity.

Five participants vividly recollected experiencing themselves as changed when they began to interact with the environment following injury. Although they did not speak about this in great depth, they were able to recall the physical circumstances and the emotions they felt with remarkable clarity, despite the passage of many years. For Patrick the memory will stay with him all his life. He says, "I'll never forget that first time ever getting up and feeling like I was on top of a
column of jelly or something; my torso was so uncontrolled." Similar to Patrick, Thomas, Steven, Michael and Dan all talked about their experience of themselves as physically changed. Thomas says, "Boy, your life changes. Just right off the bat you're no longer six feet tall, you're four feet nothing." Having to learn to manage his body differently was something he clearly did not expect, and suggests that initially he did not fully understand the change that had taken place. His realization that it would be necessary to take care of his body differently implies his appreciation of the changes in his physical self and his experience of himself as physically changed. "That was a shock to me," he says, "to realize that you have a routine you have to go through, you gotta watch your diet, you gotta drink so much fluids for bladder infections; what are you talking about, you know?"

Steven and Michael both talked about confronting the physical changes in themselves as they began to interact with their environments. Steven's animated and emotional description of his experience in physical and occupational therapy make it clear that he found the physical change in himself overwhelming.

I just couldn't stand having to learn how to sit up, and falling over and cursing those poor physios. I told [them]...it's not you, it's frustration; it's at myself. What's wrong? I should be able to do this. God, I should be able to put a little marble on top of whatever it happened to be....Can't even get a hold of it. What the hell! Smash! Right across the room. Let me out of here. I'm not touching that anymore. Get me out of here....I just set my mind and that was it. I wasn't doing anymore that day because I was so frustrated.
Just as Thomas did not initially appreciate the change that had taken place in his physical self, Steven also implies a similar lack of understanding, not knowing why he could not do things he "should" have been able to do.

Michael describes a deepening awareness of the extent of physical change as he became increasingly more active in his environment. When he began some basic physiotherapy in the hospital setting before moving to the rehabilitation centre he says "I realized, okay, I don't have balance and all this other stuff." When he began to go home on visits after he had moved to the rehabilitation centre, the physical changes he had already experienced became even more pronounced. He recalled having to be carried up the stairs in his wheelchair and being transferred so he could sit on the couch. When he was back in his home environment he says, "then I became really aware of my inability to have any balance and do anything."

Michael's recollections of occupational therapy were much the same as Steven's. He says, "I found [it] very depressing because they wanted you to do these Mickey Mouse things that before you could do without even thinking and now here it was this tremendous struggle." Steven's description of no longer being able to pick up a marble and his reaction to that illustrates that how he experienced himself physically had changed so dramatically it was almost incomprehensible. Michael also describes extreme change in his experience of his physical self in a highly evocative and moving memory from his early days in occupational therapy when he was learning to use overhead loops on his bed to pull himself up from a lying position.
I remember being so weak that I couldn't even...I'd be on my back trying to reach the loop but my arm just wouldn't get to it....Trying to get my arms up into the loops, just made you feel so inadequate...so frustrating because I was involved in sports and an athlete, and a good athlete. That really led to getting me down...you know, going from being very involved in sports and then not even being able to lift my arm into a loop.

Dan's early experience of himself as changed came about not through his interaction with the environment, but rather through his inability to interact, other than verbally. Due to his high level of injury, his physical ability was extremely limited and while he did not make any progress, he was aware that others around him were moving ahead. "Everyone else was getting better and I was just going nowhere," he says. "All those people I was in hospital with. You get to know. You see them progressing and I'm not. Pretty depressing." Dan, too, describes a dramatic change in how he experienced himself physically. Talking about his time in the hospital, he says,

I watched soaps for the first time in my life. It was all I could do. You couldn't turn the channel so you just kept watching one after the other. Oh God, they were boring. It was awful. Very hard because I was very active before. Played baseball, racquet ball, avid skier; did all that; always doing things. I never watched TV.

Participants provided concrete descriptions illustrating their experience of themselves as physically changed, and for Michael, Thomas, Steven and Dan it was evident that there was also a significant disruption in physical identity. Michael's identity as an athlete, Dan's as an active individual, and Thomas' identity as a person of a certain
stature were experienced as no longer compatible with their physical status after injury. Steven's reaction to his experience of his physical self after injury clearly demonstrates his identity as an able-bodied person capable of carrying out everyday tasks had been disrupted.

Four participants indicated that they experienced a disruption in their social sense of self after injury, in that aspects of the social self became suppressed by identification with disability. Other participants' recollections of how they felt in social situations support the contention that their social identities became destabilized, but whether they actually experienced themselves as changed socially or whether their social selves became less stable as a result of strained interactions in a difficult social environment is not clear. Their descriptions do indicate that they experienced a precarious social environment in which they often felt a separateness between themselves and able-bodied persons. William describes this when he talks about his first time going to the park.

I hated people staring. Like, what are you staring at, you know? I'm in the chair, I got the two legs, I got arms, I got a body, and I got a mind and I got a mouth to speak. What the hell is wrong with you guys? But yet, you don't know what they're thinking. They might think, 'well, guy in the chair must be kind of wacko or something.' They don't know and I don't know what they're thinking.

William's experience suggests there is a mutual confusion about social interaction. It demonstrates that physical difference forms the basis of the separateness, but confusion about social difference creates a sense of social separateness. Greg, too, talks about this.
If I enter a room [full of] strangers and I'm sitting in a chair I'm just a little more self-conscious 'cause people think 'well, if he's in a chair...'....They don't know my disability; they don't know what I can do; they don't know what I can't do; they don't know if I'm mentally retarded; they don't know.

Patrick too, speaks poignantly about people's lack of understanding about who he is.

It can just get a bit demoralizing sometimes to be seen as this pitiful creature with a disability when that's not who I am at all....I'm just aware of people on the street who can't meet my gaze or are just clearly so uncomfortable, that it's sort of discouraging, you know, saddening and so unnecessary.

Thomas also found that people would avert their eyes when they encountered him. He talks about his experience after leaving rehabilitation.

I spent a lot of time wheeling down the road and looking at people and seeing if they noticed me; not that I'm disabled, just to see if they would notice me, and wonder what was going through their minds....Eyes would just wander, you know, looking, 'oh I didn't see you' type of deal.

That Ann experiences a separateness between herself and others comes across clearly when she says

One of the things I hate...is the being stared at...I've learned how to deal with it....I do a lot more ignoring than I used to do. I've learned that it's not my disability, it's theirs. I'm not responsible for what they think....If they don't choose to make the next step, then I'm not going to.
Feelings of self-consciousness in social situations were expressed by six participants. When such feelings were experienced and how long they persisted was unique to each individual. Michael talks about the outings that were organized in rehabilitation. He says,

I really didn't take part in a lot of them. I didn't want to go out. I just didn't want to be seen. It was such a struggle for me to push the chair. I just had this feeling that everybody was staring at me. I kind of really withdrew.

Feeling self-conscious about the way he looked, Dan says that after leaving rehabilitation he "wouldn't go out anywhere." He says, "didn't like the way I looked; didn't like looking at myself; didn't like mirrors, no, forget it. Well, you know, you get the quad gut and...you're in a wheelchair." When he did go out it seemed to him that everyone was watching him. "The way other people look at me, able-bodied people, when you're out in public. I had to get over that....It's just getting out there and doing things, that's what gets you over it." Steven describes overcoming his self-consciousness.

I got used to the idea of going out with an electric chair and people not really looking at me that much, 'cause when you first go out you always think the world's looking at you....I guess it didn't take me that long. We went out probably two or three times a week to a bar. I got rid of my fear of being in a chair in public.

Bob's self-consciousness comes through when he describes what he imagined might happen when he went out to a restaurant for dinner by himself.
The fear was perhaps rejection. Just 'spasing out' (having a muscle spasm), embarrassing yourself first of all was the biggest fear. Just people, you know, how they would react to you. You know, if you cruise into a restaurant and you sat there and then people at the next table decided to move four tables away. That's the scenario that was in my mind....The fear was real at the time I remember, but now I laugh about it, like, what was the big deal about that? But until you do it once or twice, it's a big deal....One just gains confidence by doing it I guess.

Seven participants either made direct reference to or alluded to their identification with their disabilities. It was evident that initially, their disabilities were central to their self-definition. Susan did not speak about her feelings in social situations, except to say her self-esteem was adversely affected in some public social interactions, but that disability was central to her sense of self is clear. She says

If I was going out, well, what does that mean because I use a chair? Or if I want to go buy clothes, well, what kind of clothes can I buy because I now use a wheelchair? I mean absolutely everything was geared to the fact that I used a wheelchair and had an injury. I don't know, it was just first and foremost in my mind.

Greg acknowledges that his self-conscious feelings in a social situation are directly related to him being in a chair, indicating that to some degree, he negatively identifies with his disability. He says,

I'm very self-conscious when I wheel into the pub or something, very self-conscious that I'm in a chair and everyone else is standing. I go there two, three times a week and some people are regulars there and they see me. But I'm still very self-conscious.
For Michael, Dan and Bob, a negative identification with disability is evidenced by their responses to social situations as well. As previously indicated, Michael and Dan both experienced feelings of self-consciousness, and the social withdrawal and self-imposed isolation that resulted suggests that they identified with their disabilities so strongly, and disability was so central to self identity, that the social self became suppressed. Bob’s response of "absolute amazement" to his discovery that he was still an attractive member of the opposite sex illustrates that his identification with disability suppressed this aspect of his identity. He says,

   It was quite a revelation to me that a female would find me attractive or want to spend time with me. That was, like, 'wow!' 'Cause I would have bet a million to one that that would never happen again. So that was huge for me to find that out.

As a result of their identification with their disabilities, Michael and Dan became disconnected from their social selves and Bob alluded to his disconnection from one aspect of his social identity. The most profound example of the power of disability to consume one's identity, however, comes from Steven. Experiencing himself as dramatically changed physically, and anticipating total social rejection, he says,

   I thought that after I had the accident, nobody would ever look at me again....I didn't think of myself as a human being for a long time because of the chair. How long was it before I went out in public in a wheelchair? It was probably a year.

   While all participants made reference to their disability being associated with feelings of discomfort in the social realm, Michael, Dan,
Steven and Bob described a disruption to social identity in that the social self was overshadowed, to various degrees, by their identification with disability.

To summarize, participants' descriptions have indicated that as well as disruption to the social self, characterized by an overshadowing of it by identification with disability, disruption of the physical sense of self was also experienced. This occurred when participants' pre-injury physical identity clashed, usually severely, with their physical ability after they were injured. This clash became evident as they began to interact with the environment and experienced themselves as changed. While half of the participants indicated they experienced such a disruption in either physical or social identity, or both, all experienced uncomfortable social interactions which may have resulted in destabilizing, to some extent, their sense of social self.

**Connection to self.**

Participants' recollections of their experiences included only very brief character descriptions, but these were sufficient to show that their core sense of themselves, or core aspects of their personality, did not change as a result of injury. When I refer to core aspects of self, I am referring to the qualities of self that contribute to self-definition; to who a person conceives him or herself to be. These qualities are valued and considered highly important in terms of self-definition. They are qualitative descriptors of self such as, independent, adventurous, sexual, intellectual, impatient, curious, solitary, and so on. Core aspects of self can find expression in any number of ways. This is different from Charmaz's notion of the entrenched self which has been likened to core self (Yoshida, 1991). According to Charmaz (1987), the
entrenched, or core, self "represents patterns of action, conviction and habits built up over the years" (p. 302), whereas I contend that core aspects of self are represented by patterns of action, conviction and habits. I associate self-identity, which includes core aspects of self, with her description. Although a disruption of identity may occur after injury, nine participants indicated either that their core sense of self, or core aspects of self, remained the same. Patrick did not speak about a distressing disruption in self-identity as did others, but he acknowledged that his identity had altered in that he now identified as a person with a disability. It is as if his identity expanded to include his disability, but his core sense of self remained unchanged. He says,

Obviously my self-identity has changed because I've had to accommodate this disability and it has necessitated, to a certain extent, change in the focus of - or maybe not the focus so much as just the manifestations - of what I'll be doing. I certainly don't think that my self-identity has been severely damaged...You know, I still feel like me and like a whole, multifaceted person. It's just that I've had to deal with this thing.

Greg makes a direct assertion that people's personalities do not change as a result of injury, indicating, "their personality is the same before their accident as it is after." Bob says the same thing in more graphic terms, and once again his humour comes through. "I guess if you were an old miserable coot before, you're going to be that way after", he says. Six participants identified themselves in terms of a particular trait that had existed preinjury and spoke about its manifestations post-injury, indicating that aspects of personality remained unchanged after injury. Talking about his experience when
he moved back to his former place of residence after rehabilitation, Bob says, "It was a challenge but, basically my personality didn't change. I still wanted a challenge."

Ann's description of the ultimate stability of personality also supports the notion of identity becoming destabilized after injury. With remarkable eloquence she says,

When you become disabled, your whole image of yourself changes, and not for the better. And so you have to go through whatever you have to go through to get to the stage where you start the long, painful process of realizing that your body might have changed but your soul hasn't. You're still you.

She talks about having led a "very solitary" life before her injury and her recollections of life since her accident reflect her continued expression of herself as a person who enjoys solitude. She described living with other housemates in a shared home as a situation which did not work well for her. When she moved into her own apartment, she says "I was doing something for myself and that's always been my style. I like living alone." She emphasizes the importance of spending time by herself when she talks about her current living situation. "I can be fairly independent," she says. "I still need an attendant but certainly she can go off and leave me for hours at a time, and I really prize my time alone."

Steven did not lose his identity as an independent individual as a result of injury, and despite his dependence on others for physical assistance, he continues to express his independent nature. He says,
I've always been very, very independent. I mean, to the extreme, independent...."I'm still very independent. Like, I go out and do all my own shopping. If I have to go out up the street, I'll take my chair and drive up there if the weather's nice. Like, get me in my chair and leave me alone until I call you.

When Dan speaks about himself, it is evident that injury did disrupt his sense of himself as an independent person. It is also clear, however, that he did not lose his connection with this core trait, and as he progresses through his experience, he finds ways to express it. He says,

I've always been very independent, so it's been really rough not being that independent....I have a hard time asking for anything. I still do. That's me. I tried so hard all my life just to be independent....I try to find ways that I can do everything myself. Have lots of water left out so I don't have to keep asking. Got an electric leg bag emptier too now....I feel more independent today. Oh, it's been great. Just with that little bit of..., with the leg bag and [being able to feed myself]. That's a big boost.

Similar to Dan discovering ways to express himself as an independent person, Michael found expression of a part of his identity when he began to work in an environment that encouraged expression of his leadership qualities. "Part of work was leadership," he says. "So people looked after me for getting questions answered and that helped...because before in my life I was always kind of a leader."

Participants' experience of connection to their core sense of self was unique to each individual. In Patrick's case there appeared to be very little disturbance to the connection, while Steven's was so
severely disrupted he stopped thinking of himself as a human being. No matter how tenuous the connection, all the participants who spoke about the effect of injury on self-identity indicated that ultimately, it was still there. William was the one participant who did not speak about how his self-identity was or, more particularly, was not affected by injury. This is of interest, considering he was injured in early adolescence, the developmental stage of identity formation. In addition to being hurt at this time, for the remainder of his adolescence and into early adulthood, he did not have the interaction with his peers which is so important to the task of forming identity. With his core sense of self just beginning to develop at the time he was hurt, it is not surprising that he did not speak about it remaining unchanged despite his injury.

Connection to competent self.

While participants noted very different character traits they continued to identify with after injury such as solitariness in Ann's case and adventurousness in Bob's, it was interesting to find that all participants spoke about experiencing themselves as competent. Dan mentions the importance of having an attitude of openness to options in achieving a sense of competence. He says,

My attitude's a biggie for me. I mean just having a positive attitude, seeing that I can do things and compete, be productive again....I can get a job and stuff. I can be productive 'cause I am being productive at school. So I can compete against able-bodied people just as well as anybody else, so that's great.
Dan connected to his competency through his accomplishments in school and for Greg, the connection was made through his involvement in sports. Pointing out the link between one's sense of themselves as competent and self-esteem, he says,

The only activity I really did was the wheelchair sports and it was fun to participate in it and be competitive and see how far I could go; if I can be really good... It's something to excel in and something to help with your self-esteem... It's a big self-esteem issue when you break your neck or back 'cause you're a minority in society.

For Michael, starting back to work where he was accomplishing things and interacting with others was a very positive experience. "That's when I really accepted... that I, as a quadriplegic, was a functioning human being in society," he says. "It just increased my self-esteem and self-worth. [To] actually get paid for what you were doing, just made me feel like I was a contributing member of the community."

Bob doesn't work because of financial disincentives, but he talks about the option of volunteering bringing much the same satisfaction.

I could feel quite good about myself, successful, contributing to society, by volunteering somewhere. I'm contributing to society, I'm interacting with people, which is important, I'm getting out of the house, which is important. All the things they mentioned [in rehabilitation] why you should go to school or [get a job] you can apply to any volunteer career. It would make you feel good about yourself.

Ann described her volunteer work with the organization she is involved with as "a constant joy", providing her with a sense of fulfillment when the things she and her colleagues have been fighting
for "come to pass". Like Michael who talked about the fulfillment of paid employment and having accomplishments at work, through her volunteer job, Ann also experiences a sense of accomplishment that is basic to a feeling of competence.

For Michael, part of the fulfillment of work came from earning a pay cheque, which is essentially a form of recognition for competently carrying out one's duties. Being seen as competent is something Susan and Patrick also talk about. Susan's first job after her injury was a good experience that helped her connect with her sense of herself as a competent individual.

I was being productive and on the way to being self-reliant again...I was being relied upon and being reliable and resourceful and productive; being responsible, or getting done what I had agreed to do. Having somebody trust that I can do it as well.

Patrick's involvement with many community organizations, in addition to his full-time employment, reflects how important it is to him "to be a responsible member of the community." Being seen as a capable person who can be relied upon is obviously also very important to him. He talks about his participation on two volunteer committees.

I work hard to pull my weight....I guess I'd have to admit that it's important for me to make sure that I am pulling my weight and that I'm not perceived to be slacking off; that I'm contributing equally with other members.

Participants described a relationship between their sense of competency and being able to be interactive and involved with others in a meaningful way. Whether through paid employment, volunteer
work, or recreation, all participants found a way to express themselves as competent individuals.

Affirmation of self.

Experiencing changes in the physical and social self, as well as changes in the social environment, are factors that contribute to a disruption of identity following injury. Participants' recollections of powerful feelings of self-consciousness reflect their identification with disability, and that initially disability was the central focus of self-definition. However, six participants made statements that demonstrated unequivocally, that disability was at least secondary, if not inconsequential, to their sense of self. This suggests that a shift in the balance in the relationship between self and disability occurs as the experience unfolds, whereby identification with disability weakens as the connection to self strengthens. Where disability once overpowered the self, participants' indicated that not only did their sense of self remain essentially unchanged, but their connection to self eventually became strong enough that it overpowered disability. That the self dominates disability in terms of self-identity is evidenced by the striking affirmations of self expressed in participants' descriptions of this shift.

While at one time Michael's identification with his disability led to his social withdrawal, he comments that "it was about 14 years before I totally accepted my disability in terms of not even thinking I was disabled", illustrating that he no longer associates his disability with his self-identity. The predominance of his sense of self is clear when he expands further on his understanding of the meaning of acceptance of disability.
It meant I was able to go out when I wanted to go out and not worry about what other people were thinking; not caring what other people thought....Everybody who talked to me talked to me as a person, not a person in a wheelchair, not a person with a disability....The fact that I used [a wheelchair] for mobility was just how I got around. It didn't come into what I had to do or what I thought or my social interaction with other people....When I'm talking to someone I don't talk to them thinking 'okay, I'm sitting in a wheelchair and paralyzed'. I'm holding a one-on-one discussion with someone and that doesn't even enter my mind. I don't think the fact that I'm a person with a disability comes into that at all.

Ann is very aware of the potential her disability has to overshadow her self. Her conscious efforts to prevent that from happening show that her sense of self takes precedence over disability in terms of self-definition. She says,

I've learned that someone in a wheelchair has to be twice as conscious of the way they look as someone who is not in a wheelchair, because the wheelchair's the first thing people notice....There's a certain look I want for myself and I really have to stress it....You want to make sure that your personality overrides the chair.

She also makes it clear that disability is of very little consequence to her. Talking about finally moving into her own apartment, she says,

I almost picked up where I left off [before my accident]. The only changes were that I didn't walk anymore and I had an attendant now. Now those seem like big changes...but they've got to be taken in context. I was more or less out on my own; I was going to school; [I was doing] all the things, basically, that I'd been doing before.
Susan described the extent to which disability became the focus of her identity when she talked about it being first and foremost in her mind in everything she did. It is obvious that the influence of disability on her self-identity has changed radically when she talks about turning points in her experience. She says,

I'm sure there's lots of turning points....I guess it gets confusing because at some point it really doesn't have anything to do with the disability anymore; it's just life....I'm still learning new things but it has nothing to do with being in a chair anymore. I mean, I'm learning them as a person who uses a chair but if it's something I didn't do before, well, it's just something new I'm learning.

Through social interaction with others, Thomas overcame feelings of self-consciousness he experienced when he moved into the community and came to the realization that the only change in him was physical. He describes "going out to the pub...for lunch or dinner...to see if the guys play pool; meeting people; realizing that, you know, I'm only two feet shorter than I was before, nothing else has really changed much." Not only does what he says support the notion that people's core sense of self is not altered by disability, but because he talks about coming to a realization that he has not changed other than physically, the implication is that he no longer identifies as strongly with his disability as he once did. Steven, who did not think of himself as a human being after he was injured, talks about "getting back out there" and "realizing that [he is] a person", indicating a dramatic shift in the focus of his self-identity. Although his sense of self became severely disrupted after his accident, through his social interaction in
the years that followed, it grew stronger and his identification with disability weakened.

**Reflection of self from others.**

Given that all participants described encountering an uncomfortable social environment after injury, and that this may have destabilized their sense of social self, it was not surprising to find that they were highly aware of how others responded to them. Their perception of how they were seen by others had the potential to greatly influence their self-identity. Susan's experience provides an excellent illustration of this, as well as giving us insight into the process of restabilizing self-identity.

The biggest thing about having a disability for me is that kind of conflict within myself because logically I know that I'm okay and I know that I'm basically the same person, but then...the perceptions and ideas that came into my head - I don't know how - through media and just through life, told me that I wasn't okay, and it was a constant battle in my own head....So people's comments would really affect me....So [when someone said] to me 'We know you don't want to be a burden', just automatically I thought, 'Oh shit, okay, that's what I am. I'm a burden. That's what they think I am'....I felt like I was. I felt like, 'yeah, okay, well, is that how they see me?'

William fights much the same battle as Susan in grappling with his self-identity, and clearly the conflicting ways he perceives others respond to him are influential.
I still look upon the society today that they still treat you like you are in a wheelchair. Like, there's a guy in a wheelchair, 'I guess this guy is kinda weird, kind of nuts'. And then there's lots of people, they go 'like this guy has actually got some marbles up there. Look at his social skills.' Where do you go? You know, there's always that self-doubt.

Susan's and William's experiences show that establishing a comfortable relationship between one's sense of self and disability can be a difficult struggle. As has been said, participants indicated that engaging in social interaction helped them overcome the self-consciousness arising from identification with disability, and we have seen that the focus of identity shifted away from disability toward the self as they progressed through their experiences. Receiving a reflection of self from another, as opposed to receiving a reflection of the disability, was an element of social interaction that participants found to be very positive. Seven participants recalled a specific social situation in which they perceived that they were seen by others for the person they were, not for the disability they had. The importance of being in an environment in which she is seen for who she is comes across when Ann talks about what motivated her to go to school when she was living in extended care.

Most of the reason why I was going to school was to escape. When I was at school I felt like Ann, not bed number whatever. Then I was Ann. I wasn't somebody with a high spinal cord lesion.

Michael's first job after his injury was positive not only because it was there that he found affiliation with other people with disabilities, as
previously mentioned, but he also received reflections of self through his interactions with co-workers.

I got to know the secretary and all [the staff]....They didn't care that I was in a wheelchair or anything....I had some positive experiences there because I developed almost a romantic relationship [with one of them]. Just the fact that she liked me for who I was and me knowing that I was a quadriplegic. That was a real positive experience.

Similar to Michael, Steven discovered that others could see beyond his disability to the person he was when he began a relationship for the first time after he was injured. "We went out and had coffee and talked a lot together and just hit it off and got together physically....To me it was a high point that she could still find me desirable and not put me down", he says. For Steven who thought no one would look at him again after his accident, "having people see [him] as a human being" told him "that he was still amongst the living."

Susan says that people's comments affected her more negatively than positively and it is interesting to note that the ones that had a negative impact were not reflections of self but were reflections of disability. Perhaps the starkest example of these was a close relative's comment, which she heard indirectly, that it would have been better if she had not survived her accident. "Cause they just had no idea of what was possible afterwards, but it just gave me a really good picture of how I thought people saw me", she says. By contrast, one of the first positive comments she remembers came from an interaction in which she was being treated "normally", or as anyone might be, regardless of whether or not they had a disability.
One of the first positive ones was in the hospital; to have the nurses call me 'lard ass' when they transferred me and stuff, and joke. It was just normal. It was being normal and I really, really appreciated it lots. We were just having fun and it was all said in fun and I knew that. It was good. I liked that a lot.

Obviously such remarks were far from insensitive or offensive to Susan which suggests a good rapport had been established between her and the nurses, and they saw past her disability and recognized her as a person with a sense of humour who enjoyed some lighthearted fun.

Michael was the only participant who stated explicitly that having someone see him for the person he is helped him strengthen his connection to self. He talks about how having a meaningful relationship and seeing his self reflected back by another affected him. "Meeting someone that could see past the chair, past the disability, accept me for who I am; I guess to me that made me feel like a whole person, not a person with a disability." While others did not specifically identify a positive relationship between receiving a reflection of self and a stronger connection to self, it was always a positive part of their experiences.

The categories related to self-identity suggest that after an initial destabilization of identity, in which disability is the central focus of self-definition, as participants interact with their environments and gain experience, the centrality of disability dissipates as connection to self strengthens. As this occurs, participants acknowledge that their core sense of self remains unchanged, and a reconnection to competent self is made. Participants valued receiving reflections of self from others. They indicated this was an important factor in facilitating their
progress toward a restabilized sense of identity in which their sense of self clearly took precedence over disability.

Support

The two categories under this heading describe who provided support to participants after their injury, as well as how participants were supported socially and emotionally. Community organizations that provide services for people with disabilities are often referred to as community "supports", and while eight participants mentioned utilizing these, references to them were factual and were confined to very brief, practical description, such as using accessible transit to commute to and from work. These supports are not included in this category. Social and emotional support, however, was a theme all participants spoke about, and all but two returned to it repeatedly. Only one person did not speak spontaneously about support and was asked if it had been an important part of the experience. Generally others' attempts to be supportive were welcomed and highly valued, but William, Patrick and Susan also talked about instances when an offering of support was, in fact, non-supportive. These are described in this category in that they contribute to a fuller understanding of the nature of support.

The providers of support.

For Greg, the experience of living with spinal cord injury has been made more difficult by virtue of the fact that he "just didn't have enough support." As he says, it is "very, very important to have lots of friends and a big support network when you have a spinal cord injury." A greater appreciation of this can be gained from his description of how the absence of support affected him. He talks about arriving at
rehabilitation, having been accompanied there by a friend who, very soon after, left.

I remember feeling really scared and, you know, don't leave me, don't leave me, I'm all on my own and I don't know anybody here. It was pretty devastating. 'Cause I really didn't have enough support. I just didn't have enough family and friends and stuff. So, I basically went through the whole experience by myself.

Eight participants confirm what Greg implies, and identify family and friends as the primary providers of support. Five talked about receiving support from both friends and family, two from friends only, and one from family only. One other participant did not mention either, but spoke about being supported by professional advocates. Including Greg, then, four people did not mention any long term support coming from family, although they may have talked about family being present immediately after injury, and three did not speak about being supported by friends. Half of the participants identified between one and three particular people, who were especially important to them in terms of support.

Clearly, it was essential that the provider of support had a close, meaningful relationship with the participant in order for the support given to be effective. Three participants described rejecting support, in each case offered by a stranger. Steven talked about seeing the psychiatrist upon his admission to rehabilitation and receiving nothing more than a drug prescription. "In that first little visit he gave me anti-depressants. He didn't even know me from Adam and he gave me anti-depressants. He didn't know if I needed it or not. So I never went
His words illustrate the importance of the relationship, as do Dan's when he describes having a similar experience many years later when he was in rehabilitation. "They used to take me to the psychiatrist and the psychologist but I just told them to go away. 'Don't want to deal with you guys. What do you know?'", he says.

The nature of support.

Three forms of support participants described were emotional availability, motivation and what I have called accompaniment. Eight participants talked about receiving at least one of these during their experience. Accompaniment refers to support being provided by the physical presence of another in social situations, or facilitating and being present at an activity that is emotionally beneficial. For William, Dan, Patrick and Bob, this was an important support. William describes the accompaniment provided by his friend when he moved into his new apartment and suddenly found a whole new world of opportunity open to him. "He helped me quite a lot, to take me out and socialize and do things with him", he says. Dan was supported in much the same way by a close friend when he was just beginning to see that new opportunities were possible. He explains.

She's very sneaky about the way she does things. She puts a little hint here and there; 'well, maybe you could do this or that.'...She's helped me out a lot, got me back in school, showed me that that was the way to go, 'Get out there! Live!' So she's taken me out quite a bit to restaurants and malls and just getting me used to being out with people. She's done that for the last two years. It's been great.

Patrick and Bob describe receiving much the same support when they were in the rehabilitation centre. Bob says,
Close friends and family would always come and rescue me for a weekend and take me out somewhere; just get me out of the institution...It's kind of a first taste of what life is going to be like outside the institution. So those times were very important. Just to get away; just to be normal. So those [times] were huge.

For Patrick, the support came from a good friend.

She was able to use the [rehabilitation centre's] van to transport me out of there. I remember a couple of times I just felt like I had to get out of there and so we went off and did whatever. So that was a really important support to me.

It is important to emphasize that accompaniment refers to doing things with people and not to doing things for them. In fact, William's experience of having his father do everything for him had negative consequences and is an example of intended support being detrimental instead of helpful. For 18 years his father was "an attendant, a father and a friend,...a cook and a bottle washer, and whatever else you could think of. He was there for me," William says. His attempts to become more independent and rely less on his father were not successful, as he explains. "It's basically, okay, your parent is there but it's time [to be more independent]. Like you're saying 'okay Dad, I'm trying now' but he says 'no it's not [time]. I'm still there for you.' Understandably, it was difficult for William when his father died and he suddenly found himself alone. "Then you start realizing things", he says. He talks about this in more detail.
It was hard. Paid your own bills for the first time ever; bought your own food for the first time, you don't know what to buy or what you're going to eat....You could call for help at any time you want but now you have to pick up the phone and dial for help....So everything was new to me. Actually it took me about two years to get used to living on my own.

Thinking about his experience in retrospect, he says "I think that I should have and he should have known to say 'okay, this is it; this is like separation, in a good way.' He describes the important difference in the support he received from his father and that which he received from his friends when he was on his own. Of his father he says, "he was a pusher, like a motivator, but yet he was too sympathetic at the same time." On the other hand he says of his friends, "There's a lot of moral support...You cry on their shoulders until they say 'that's enough; now it's time for you to step a little bit more and a little bit more.'"

The "number one" thing of key importance in living with spinal cord injury in William's opinion is to learn to rely less on others and increase one's independence, which is not surprising in light of his experience.

Akin to being unintentionally non-supportive by doing too much for someone, is imposing one's ideas and opinions in an attempt to be helpful. There is no question that Ann does not welcome this kind of "help". She says,

When someone says to me 'I know what's good for you. I'm going to tell you, or do for you, what needs to be done' without letting [me] have any input into that decision, my back goes up and I dig in my heels.
Susan experienced someone imposing their opinions on her not long after returning home from rehabilitation. "Other people's ideas of how I should cope with things, you know, and they would apply them to my life for me which I didn't necessarily appreciate all the time. People kind of figured what I should be doing with myself;...people intruding on my life in that way." Michael had quite a different experience of finding his own ways of coping and being supported in doing that. He says, "I think I was telling myself...[to look] for positive things in my life instead of dwelling on the negatives...and there were people in my life supporting that....I didn't have anybody telling me. Dan talks about his personal care attendants telling him their ideas in a non-intrusive way that was supportive.

They're here to make you more independent and they do. They're always getting ideas, 'oh, maybe we could do this a little different or maybe we should try this, maybe you could do this [but then] they let me take it from there.

The contrast between Susan's experience and Michael's and Dan's shows the importance of respecting the agency of the person one is trying to support.

Six participants found being motivated by others to be an important form of support. For Bob this was a crucial part of his experience. "To be pushed and to push yourself is probably the most important thing I've learned," he says. He describes being supported by friends who motivated him to go out and socialize, despite the excuses he found to stay home.
I found I had to push myself to get out and that was the true value of my friends. I would say, 'nah, I don't feel good, I got a bladder infection, nah, it's raining'. Well, they'd push me, 'come on, just let's do it!' I'd go somewhere and 'wow, this is great, this is just great. I'm so glad you talked me into it.' So they'd remember that for the next time I'd be whining.

Dan talks about his friend's, as well as others', attempts to motivate him.

[I got] a lot of help from him. He was always, 'come on Dan, you gotta do something, you gotta do something; you can't just watch TV all day. Get out there'....Sometimes you gotta be blunt. 'Get out there; you've got so much potential. Don't let it go to waste'. A lot of people said [that]. And you have to see your potential again, which I hadn't for a lot of years.

The motivating power of friends was something Thomas benefited from as well. He talks about the support he received when he was going through his rehabilitation program, which friends would sometimes sit in on.

They were very supportive and going 'oh yeah, Thomas, see that guy over there? You'll probably be doing that in about a month or so'. And I'd go, 'ah, yeah, yeah, yeah'. And it made me want to work harder to get to that level of accomplishment for my friends and for myself.

Steven also describes the effectiveness of others' attempts to be motivating when he says, "you've got friends; then they give you that spark, you know, 'let's fight it'. They are there for you so why not just go along and do the best you can do?" Just as Bob came to appreciate the true value of his friends, in part at least, through the support they
gave him, Steven expresses the same thing in his imagining of what life would be like without his friends. "I guess about four of my friends, if it weren't for them I think I would have given up. You know, forget it. I think that's the most powerful thing is the friendship." What Steven suggests is that support is inherent in friendship. Greg certainly agrees with this when he says that had he had the support he needed it would have been "to have friends" who were supportive by doing "just everyday things. Just being a friend and doing things together."

Steven and William both made reference to being supported by others being "there for them", although as we have seen in William's case, this can become too much of a good thing. Bob alludes to the emotional support others provided to him by "just being there when [he was] down." He did not explain specifically how people were "there for him" but Dan's experience when he was in the hospital illustrates that, at times, nothing more than "being there" is needed. He says,

I remember waking up one time and my older brother was there. It was one o'clock in the morning. He was just sitting there. That was pretty nice. He was just there. We never talked about it. He just had to be there, that's all. It was good.

His younger brother was also supportive by being there everyday. "He didn't miss a day", Dan says. "That was pretty wild. He was always there." Steven had a very similar experience when a friend showed him his support by visiting him in the hospital at twelve-thirty in the morning. "That's a friend", he says. "It's all to do with friends to survive." Bob points out that an important part of the emotional support he gets from friends being there for him is "knowing that they're going to be there for [him] in the future." This is something
Steven talks about as well. He explains that one way his friends support him is by "staying when you're really being a jerk. It just gives you strength to know that somebody's there, that they believe in you and that when you come out of it, they're still going to be there."
The constancy and stability of support was something Michael, Thomas, Dan and Patrick also mentioned indirectly. Michael says, "certainly the parental support was always there, was always positive", and for Thomas as well, family was "always supportive." "I...have a great family. They've always been there", Dan comments, and Patrick says, "I had the support of the family and I know that I really valued that. I still do."

Being willing to listen when participants wanted to talk was another way others demonstrated emotional support. Thomas says, "the support was there when I needed it. When times were down a friend would talk to me, which was great." Patrick recalls relying heavily on a long-time friend for support. Not only was she there for him in that she came from out of town and stayed for the duration of his rehabilitation, he remembers "sharing a lot of the hard times with her." When Susan talks about the difficulty she had in developing supportive relationships when she relocated, again the importance of having a close, meaningful relationship with the provider of support is accented.

I hated it when I first moved out here. It was a big city and I found it hard to develop relationships that weren't really just kind of...superficial....I missed my girlfriends. People that I'd gone through school with and that I knew really well and could phone up and say anything to, and I could get support from when I needed it and give support to.
In all, six participants spoke about being supported emotionally by friends or family, either by their being present during difficult times or by their being available to talk.

Patrick makes the important point that support which may once have been helpful, may become inappropriate as an individual progresses in their experience, and instead of having a positive effect, it may be negatively received. Speaking about others acknowledging the fact that he is doing well, he says that at the outset of his experience when he was just trying to deal with his injury, it did 'bolster' him. As he says, "I mean somebody tells you that you're doing really well, or dealing with something well, you can't help but feel good about that." Since then, however, he has moved far beyond just dealing with his disability and is living his life "sort of on top of that, and being involved; staying involved." Now, when people tell him how impressed they are with the level of independence he maintains or with the degree to which he contributes in the community he says,

Sometimes I don't receive that as well as I might. It's sort of embarrassing in a way to have people say that. I guess just 'cause it focuses on my disability....I'm just of two minds about that because I am proud of that accomplishment and I do appreciate the acknowledgment but I guess it sort of verges on patronizing. I guess it just has to do with people making a bigger deal of [my disability] than I feel it is.

Patrick was earlier quoted as saying that he has had to "accommodate" his disability into his life. His choice of words makes clear that his life takes precedence over the disability. He did not say he had to accommodate his life to his disability. Comments such as people telling
him they are impressed with his level of independence demonstrate a lack of appreciation that he is living his life first and second, he is a person who has a disability. It is as if he is recognized first for dealing well with his disability, and then for living life fully. The life he leads is seen first of all as a testimony to how well he is dealing with his disability, rather than being first and foremost an expression of who he is.

There are several indicators that support was an extremely important component of participants' experiences, beginning with the fact that references to it arose without provocation in all but one interview and eight people mentioned it more than once. Half of the participants specifically identified support as either the factor that was most helpful in their overall experiences or as the one that helped them rebound at the critical turning point.

Bob used the words "wonderful" and "huge" to describe the support he received. Thomas described his as "unbelievable" and "overwhelming". Steven says without his friends "he wouldn't make it" and Dan points to relationships with friends and family as "the most important thing." Such emphatic words and phrases demonstrate that support had an undeniable impact, and as many of the excerpts quoted in this category make clear, it is a valued and generally positive part of participants' experiences. Greg makes multiple references to a lack of support, notably when he described times of heightened stress, such as the transition from hospital to rehabilitation and rehabilitation to community living, and he repeatedly associates the difficulty he encountered in his experience with the absence of support. His
references to the negative effects of a lack of support illustrate the importance of being supported appropriately.

Simply being present, being available to talk about good times and bad, saying encouraging words, and doing things with participants, but not excessively doing things for them, are the ways friends and family showed their support to the people in this study. Support did not take the form of someone else changing things in participants' lives. It took the form of facilitating their ability to make desired changes, by providing what was needed, whether that was the security of family ties or deep-rooted friendship, or arranging a weekend away. Ultimately, the participant is the agent of change and is the one who bears responsibility for actively initiating it. As Thomas says, "[Life] is what I want to make it. The opportunity is all out there for me but I got to be willing and able enough to go out there and use what's available." Just as others cannot actually make the changes participants want in their lives for them, William makes the point that support cannot be forced onto them either. He says, "It's up to you [whether or not you take it]....No matter what type of support there is out there for you, even your loved ones, it's got to be up to you. And if you don't take it, then what is there? There's nothing but hell." It struck me as I read each person's story that support acted as a cushion that made the experience a little softer, less stressful and therefore, somewhat easier for participants. William's statement suggests this is true. Bearing in mind the supportive nature of friendship, it seems Bob would also agree. "Life has been, and still is, rocky and tough as hell," he says, "but it's...comforting when you have as many friends as I do."
The two categories describing the aspect of support in participants' experiences identified friends and family as important providers of support, and outlined three ways participants valued being supported. Along with these, intended support which was, in actuality, perceived as non-supportive, was included in the results pertaining to the nature of support.

**Summary of the Experience of Living with Spinal Cord Injury**

The results presented in this chapter thus far reveal the complexity of the experience of living with spinal cord injury. Participants described an experience of moving through five points of passage, during which time they engaged the processes of navigating their experiences and restabilizing a destabilized sense of identity. Woven throughout the whole experience was the crucial element of support. This, along with finding affiliation with other people who have a disability, having an attitude of openness to options and actively pursuing options, and receiving reflections of self from others were seen to be helpful to participants.

Participants spoke very little about what hindered the experience. Health issues, finances and problems with equipment were mentioned most frequently as being obstacles. Some participants pointed to parts of the experience such as the social discomfort experienced, or the critical turning point, while others indicated personal characteristics like a propensity to procrastinate, and lack of self-esteem. Although given multiple opportunities to comment on what the obstacles were, participants did not have much to say in answer to this specific question, and were not inclined to elaborate on any they did identify. This is possibly due to the fact that in the
context of conveying a whole life experience, the hindrances participants believed were most salient were the setbacks they encountered along the way, and these were expressed as natural elements of their story. Considering this, it is not surprising that, after telling their stories, participants had little more to add about what hindered when they were given the opportunity to do so.

The Meaning of Adjustment

The complexity of the concept of adjustment was revealed not only by the diversity of the thoughts participants expressed, but by differences in the way they expressed them as well. While half of the participants had a clear understanding of what adjustment meant to them, the others did not and met with various degrees of confusion as they voiced their ideas. This was unrelated to length of time since injury. Contrary to what might be expected, greater experience of living with spinal cord injury was not linked with a greater understanding of the concept of adjustment. As Greg says, "it's a hard word to define", and Patrick certainly found this to be true as he tried to verbalize what it meant to him. "I'm having trouble conceptualizing this," he says. "I can't find words." For those who did encounter some confusion as they talked about adjustment, the tone of their speech was exploratory rather than explanatory.

Nine participants associated adjustment with the quality of movement. Ann makes reference to rebuilding a healthy self-esteem as essential to being able to make adjustments and move forward. "You can't accept change unless you're able to change everything, internally and externally," she says. It is evident that adjustment involves movement when she goes on to say,
You make your internal adjustments so that you can make the external ones as well....Until I've got the self-esteem issue settled I can't really make a valid adjustment. Anything I do will be sort of terminally tinged with doubt. You know, you'd never be able to take another step.

Greg saw adjustment as "just trying to cope with life in a chair" but he agreed with Ann that self-esteem is an influential factor. "When it boils right down to it, I think adjustment is really how well you feel about yourself. Your ability to adjust to the situation [depends on] what you think of yourself. If you think you're a good person and you have a high self-esteem, then I think things are a bit easier and you're able to cope."

Movement is a quality William associates with adjustment, and in acknowledging that it can take time to become open to options, he recognizes that a person may not always move forward.

Well, you just don't give up, I guess. And have time to adjust....It's like wearing a good pair of shoes for ever and ever and all of a sudden [they're] old and you try to throw them away but you can't because they're comfortable, but there are new ways and means of life out there; experiences....It's like an adjustment period. To me it's natural and it just comes and that's it. You strive for more.

Michael says that adjustment is "just certain ways of coping and moving on", but as he thinks further about this he then says, "I don't know if you'd call it coping. Coping just sounds like you're hanging on kind of thing." It is clear that Thomas associates adjustment with movement when he differentiates between his understanding of coping and adjustment. "Coping is usually without choice. Coping is 'all right,
can't do it. Okay, it's fine the way it is', where adjusting, in my book, would be finding things that can help you in those circumstances."

Susan expresses much the same opinion as Thomas. "Coping has negative connotations," she says. "Thinking you have to deal with things exactly as they are and there's no possibility for change; you just have to cope with it. Adjustment is change." Change is synonymous with movement in that one cannot happen without the other, and Dan points out that, in terms of adjustment, movement is a product of responding to change. To him, adjustment involves "realizing that everything is changing all the time...and you have to change with it." Ann agrees, saying, "To me adjustment means...being able to change if you have to with every situation." Michael sees adjustment as responding to the many changes he experienced after his injury. He says,

I had so many ups and downs...I think with every [one] there was a period of adjustment, 'cause there were different factors and different feelings and emotions in all the ups and downs. There were different periods of adjustment; it wasn't just adjusting to the fact that I had a disability...I had all these other complications....Certainly after every up or down, especially the downs, once you get through that there's a change in attitude, you have to adjust in some way...If you didn't adjust then you would just keep going in a spiral downward...So in order to get back on the track of being positive, or getting better from your depression, or whatever, you're going to have to make some adjustments.

What Michael is describing here is the attitude of openness to different ways of thinking about things that facilitates the pursuit of options. Bob also associates this with adjustment. He says,
Adjusting is, I guess, something corny like making the best of a bad situation. There's tons of things I can't do so I either focus on that or focus on the things that I can do and enjoy....I'm constantly monitoring my brain...to keep positive....If I didn't guard or beware of my thoughts and feelings on a daily [basis] I could easily get sucked into becoming a negative, bitter person again....You continue to adjust the way you think so you can be as happy as you can be.

Michael's thoughts bring to mind the changes in attitude that prevented participants from spiraling further downward at their critical turning point, and as we have seen, it was "turning on the positive thinking" that brought Bob out of his depression at that phase of his experience. Using the metaphor quoted earlier, William also described the attitude of openness to options when he talked about adjustment.

Six participants associated the pursuit of options, which is characterized by movement and change, with adjustment. Thomas referred to this when he distinguished adjustment from coping. Patrick says, "I think [adjustment] has to do with pushing the boundaries and exploring options...and not necessarily accepting anybody else's word about what's happening or...how to deal with things or how to do things, you know, with a disability." Dan and Steven both gave examples of change when they talked about adjustment. Steven says,

Adjustment, to me, just covers every aspect of my life....Being able to do things spontaneously, like jumping into a car and taking off....Now I have to order a bus. Gotta adjust to that....It's just everything you do nowadays, like, I automatically push a joystick to go somewhere. At one time [I] just [took] a step there.
Thomas summarizes what Steven is saying when he says, "Adjusting is ongoing. There's always something that I have to do different today, 'cause I would have done it differently when I was walking." Dan also talks about adjusting to "everyday living, everything that pops up during the day, any little thing." He illustrates this with an example.

I have to use a splint to put my fork in to feed myself. It's an adjustment. Before you could just get up, eat whenever you wanted. Now it's ask the attendant, get the food cut, put it on the plate. That's an adjustment.

Ann's ideas about acceptance seem to be similar to what Thomas thinks about coping, in that they both see them as having connotations of a static state of affairs. To Ann, there is definitely a close relationship between adjusting and the pursuit of options. She says,

I don't like the word acceptance. I feel you adjust to a situation but I've never accepted that I can't do something, because disability or handicap means to me that you can't do something. Well there's always a way; so you have to adjust. You have to adjust so that you can find that way.

Thomas identifies another component of adjustment in a definition that also describes the sense of having to start life again, which was presented as part of the disorientation phase. "Adjustment is being reborn again," he says. "Learning how to crawl before you walk, so to speak....Adjustment is learning." The pursuit of options, which in effect, can be thought of as the pursuit of change, requires an attitude of openness to alternatives, as well as learning the alternative way of doing something or thinking about something. Nine participants indicated at least once during their interview that they had learned
from their experience and Thomas, William, Dan, and Steven specifically related learning to adjustment. Dan speaks for the others when he says, "It's a learning process, a learning experience, adjustment. You have to adjust or otherwise you're just gonna go backwards, you're not going to go forward." Although others did not verbalize a direct link between learning and adjustment, learning is an implicit component of openness to and pursuit of change which, altogether, nine participants associated with adjustment, whether it was in relation to a change in attitude or a change in a method of doing something. In the context of learning how to live with a disability, adjustment involves responding to change by being open to and pursuing further change, which manifests as movement forward, or progress.

Another important component of this conceptualization is fluctuation, in that adjustment will occur as dictated by circumstances, and there will likely be times when there is no need for adjustment. This is illustrated well by Michael, as he thinks about his experience in the present. "I think I'm doing really well," he says. "I mean, I get people telling me I should drive, but I don't have the finances to redo my van...and in terms of my life...I get around just fine the way I am now, so it's not a real urge." At this time, learning to drive is not a necessary adjustment for Michael and consequently, it is not a change he feels a need to pursue. He is still very much open to future change, however. On a scale of one to ten he says, "I think I'm up there at eight and a half. I'll leave room to move; to go up, but I think I'm doing great where I'm at."
Steven's experience provides another example of this conceptualization of adjustment, and again he points out that, although adjustment continues throughout life, there are periods where there is little perceived need for it, and so little change takes place. Saying that he has had to adjust to everything "in some minor or major way" because "everything is different from what it used to be", he then says, "I've adjusted...you know, I've adjusted to everything pretty well, and when something comes up, I have to learn to adjust to it." Steven has responded to the changes in his life by being open to and making further changes. At this point in his experience, no adjustments seem needed, but he clearly anticipates further adjustments will be made if "something comes up" that requires him to make a change.

Michael shows us that eventually adjustment has little or nothing to do with learning how to live as a person who has a disability, and simply becomes a part of the life of a person who happens to have a disability. In his self-assessment he left room to move up, but the next change he anticipated in his life had nothing to do with learning how to live with a disability. Moving up, he says would be "moving from an apartment to a house, or a better apartment, bigger apartment, newer apartment." Susan has said that the new things she learns in her life no longer have anything to do with disability, and in talking about the state of mind she associates with adjustment, it is very clear that she is now just simply living her life. She says,

Adjustment for me is when I can enjoy whatever it is that I'm doing or seeing or being in the moment for what it is instead of instantly comparing it to how it used to be and wanting it to be [that] way, so therefore not enjoying it as much as I could if I wasn't
comparing it. And I don't instantly compare anymore. It's just life. Otherwise I'd be going through rehab forever.

Although she appears to be describing a static state, it is a state of mind which she connects to a certain way of feeling. She has also equated adjustment with change, and considering this in conjunction with the above definition, change is simply a part of life, and is no longer related to learning how to live with a disability, as it was in rehabilitation. When adjustment began to have more to do with life and less to do with disability is not clear. "I don't know when I stopped [comparing] or how I stopped doing that," she says. "I imagine it was just kind of gradual over time. It wasn't everything all at once. It was probably practice." Bob speaks for Michael and Susan when he says succinctly "I continue to adjust and it's just part of living."

Four participants mentioned acceptance when they spoke about adjustment and their thoughts suggest that these two concepts are distinctly different, yet related. Patrick articulates this well.

I think an important part of adjustment is that philosophical acceptance that this is what's happening and that you deal with it or you don't. To me [acceptance means] realizing that you have the disability...and nobody else is going to wave a magic wand, and this is what's happening so it's up to you now. The acceptance is, I guess, the first thing you have to do....All I'm trying to say is that that just means to me that you are fully cognizant of what this is....You can realize what's happening but not accept that that's what you want for yourself or want in your life. So then it's a matter of well, what do you do? Do you adjust to it?....I think you can adjust very well but not entirely accept.
Patrick points out important differences in the use of the word acceptance which need to be made clear when they are used in relation to the concept of adjustment. On the one hand, acceptance means being cognizant of what is happening, while on the other it means deeming what is happening to be acceptable, or unobjectionable.

Steven says that the worst part about the change in his life is being dependent on others. "I can't stand being dependent," he says "I still do not like training new attendants and I [never] will, 'till the day I die." He also says he will never get used to having no sensation below his level of injury. "That's still one of my biggest wishes", he says. Obviously, Steven would not agree that having a disability is acceptable. When he says, "you just accept it. You got no choice but to accept it", he is talking about acknowledging his disability. His explanation echoes much of what Patrick said, and supports his contention that acceptance "is a step towards adjustment"

You're battling inside yourself for two to three years until you decide there's too much energy going for this. Let's just accept it and get on with your life....Before that you're still having difficulty accepting that it takes you ten minutes now to do something you used to do in maybe two seconds. So you just got to decide, okay. You accept it....Parts of me just decided 'well, come on, it's not going to change so just accept it. No matter what there's nobody going to put a new back in you, so get on with it.

Acceptance of his disability allowed Steven to move on and as he has said, he has since adjusted to "pretty much everything." Although William did not use the word acceptance, the idea of realizing one's situation came across when he spoke about adjustment. "Don't shield
yourself away from reality," he says. "Reality is there and it's staring in your eyes at all times."

Bob's experience gives an excellent example of adjusting well to living life with a disability, but not accepting the disability. It seems he uses the word acceptance both in reference to realizing his situation and to deeming the acceptability of it. "Adjustment. To me it means just sort of accepting my lot in life....I want to be at a point where I'm at 'okay, I've accepted I can't...'", he begins, but then his thoughts are abruptly drawn away from his physical limitations and he says,

In my dreams I'm not in that wheelchair. I'm doing amazing things in my dreams. I can never sort of accept it, but you adjust to it or something....It's a frustrating thing that you're in a chair, not being able to reach that, not being able to do that. You're faced with it every day. It hits you in the face. Everyday. There's no getting around it....I'm always frustrated. I'm never accepting being in a wheelchair for the rest of my life. I think along the lines of not being disabled and in a wheelchair and can't do this. In my mind I think that I'm still twenty-five and still walking around out there, but you're always daily rechallenged by your physical limits. I don't know. Maybe it's some sort of tricky denial thing. I don't know, but I'll never say this is great. This is the best thing that's ever happened to me and I don't mind. Well, I say bullshit. I do mind. It's a pain in the ass.

The reality of Bob's situation is still something he wrestles with but he clearly does recognize it when a daily reminder of it "hits him in the face". Despite this struggle and the fact that he most certainly does find having a disability objectionable, he has found a way to adjust by "making the most of a bad situation" as he said. "If I think about [the disability] I'll go crazy," he says, but he goes on to say,
If I think about the positive things in my life, then life's pretty good....It's going to be a challenge for the rest of my life. I hope I keep this [positive] attitude. It's going to be work and I'll have to continue to put a lot of effort into it. I just know myself that I have to continually work at keeping positive. And it's work. Daily work.

For Bob, working at keeping a positive attitude has allowed him to respond to the changes he has been confronted with in his life since his injury and he has been able to progress.

It is noteworthy that for Steven and Bob adjustment does not involve dissolving all the negative associations they have with disability. Rather it appears they have found ways to resolve them, by first acknowledging them and then finding ways to live with them. Dan has done the same thing. He explains.

I had a real hard time getting used to people caring for me....I hate [having to rely on people]. I still hate it. I've gotten better with it, you know. I'm accepting it more, but I still hate it. Especially the personal care and stuff. You're always training new people...and I hate it....It helps me when I talk about it. It just makes me sort of realize that, you know, I'm in a chair, I'm going to need that kind of help, I gotta get used to it....I'm never gonna really get used to it, but I'd probably be able to tolerate it more. So it's going to be a sore spot with me and that's just the way it is and I've accepted that. That means I realize that I'm going to have a problem with it and some days I might not be able to deal with it and other days I will. I just speak to myself, tell myself 'look Dan you can't do anything about it so why worry about it. That's the way things are. Gotta train these people. That's the way my life is, let's go'.

His definition of adjustment includes accepting the reality of his situation, and he recognizes that being unable to do so interferes with
his ability to move ahead. He says, "To me adjustment is...to see me at the point that this is the way my life is now and I have to go on from this point and not let my disability hold me back....I should be able to do everything I did before, mentally, not physically, of course, to the best of my ability. There shouldn't be anything that should limit me back." Dan acknowledges that, at this time in his experience, he is limited by his attitude "in a few personal spots" and he gives the example of not being able to envision having a family. However, he epitomizes the characteristic fluctuating motion of adjustment when he goes on to say, "I think that's being realistic though. I think. It could change. Who knows?"

The parallels between participants' ideas about adjustment and many of the categories describing the experience of living with spinal cord injury lend strong support to the contention that adjustment is the course of an individual's response to change. Keeping in mind that adjustment was not spoken of simplistically by participants, Thomas' definition of it includes the notion of starting life all over again and Michael's ideas bring to mind the critical turning point and participants' changes in attitude at that time. Ann and Greg allude to issues of self-identity with their associations of self-esteem and adjustment, and Bob describes connection to self as another piece in his conceptualization of adjustment. He says, "adjusting is keeping the personality and the energy and whatever personal traits I had before the accident....To adjust is to come back to that place independent of your injury, I guess." His implication is that a destabilization of identity does occur after injury. All but one participant conceived of adjustment as involving openness to and pursuit of options, either to
bring about emotional or physical change. The fact that most participants' spoke about pursuing options in more detail than any other aspect of their experience, and that almost all of them related it to adjustment, suggests it is a very significant part of the experience.

Summary of the Meaning of Adjustment

The participants in this study have brought to light a complex, multidimensional concept of adjustment. Certainly the core characteristic of it is movement, and in terms of their experiences, this was synonymous with change and the learning involved in such change. It was pointed out that adjustment may fluctuate in accordance with the need for change, supporting the notion of adjustment as the course of an individual's response to change. The importance of clarity in regards to the use of the word acceptance in conceptualizations of adjustment was highlighted. Two very different meanings of acceptance were distinguished, and their relevance to the concept of adjustment was discussed.

Participants ideas put forward three dimensions of adjustment, and although they are not comprehensive, they are worthy of mention. Firstly, acceptance, or recognition of one's situation, was seen to influence the ease with which one was able to move forward. As Dan and Bob have shown, adjustment can continue along with the struggle to fully recognize one's situation. Secondly, much of the movement in one's experience is initially related to the changes involved in learning how to live with a disability. This requires an openness to and pursuit of options that will bring about emotional and physical changes. Lastly, as one gains experience and effectively masters the task of learning how to live with the disability, forward movement is seen to be simply
a part of life, as it is for everyone. Although it may appear that these
would follow each other as linear stages, the fluctuating motion of
adjustment and the fact that it occurs in response to an individual's
circumstances suggest that, while these dimensions may manifest
themselves in such a fashion, it is just as likely that they may not.

The conceptualization of adjustment as the course of an
individual's response to change can accommodate the complexity of
each person's unique experience and minimizes the temptation to
attach externally derived values to it. In this context, adjustment can
be accepted as a phenomenon that fluctuates in unison with the ebb
and flow of one's experience, and that branches out into the varied
aspects of one's life at different rates and in different strengths. This
idiosyncratic nature of adjustment is powerfully illustrated by Dan.
Reflecting on his experience, he says,

I think I'm at the best place I can possibly be right

now....It's taken ten years but, you know, maybe it had
to take ten years. Maybe I wasn't ready to do anything
else before. I sure didn't have the capabilities and that's
only come around 'cause my arm got strong, and a few
other things. And my confidence level got better. So I
think maybe there's a reason for everything.

Chapter Summary

This chapter presented the research results in two sections. The
first pertained to the experience of living with spinal cord injury and
outlined 14 categories of experience under four headings. The first
heading was Phases of the Experience which described five points of
passage participants passed through in their experiences. These were
Disorientation, Rehabilitation, Entering the community, Coasting and the
Critical Turning Point. The second heading was Navigating the Experience which referred to the underlying cognitive, emotional and social factors involved in participants' discovery and pursuit of possibility. Two categories fell under this heading. Finding Affiliation described an interpersonal interaction and Pursuing Options described a strategy of being open to and pursuing alternatives. Both were helpful to participants in facilitating progress. The third heading was Self-Identity and the five categories under it suggested that identity becomes destabilized as a result of injury and participants engage in a process of moving toward a restabilized identity as they pass through the phases and navigate their experience. Destabilization of Identity, Connection to Self, Connection to Competent Self and Affirmation of Self described the movement from destabilized to stabilized identity, and Reflection of Self from Others described an interpersonal interaction that influenced this movement. It was pointed out that as participants gained a restabilized identity, disability became less central to self-definition. The two categories presented under the fourth heading of Support were The Providers of Support and The Nature of Support. The providers of support were primarily family and friends, and the nature of support was variable and included accompaniment, motivation and emotional support.

Results pertaining to the meaning of adjustment were presented in a second section following those relating to the experience of living with spinal cord injury. Adjustment was revealed to be a complex phenomenon characterized by fluctuating movement, change and learning. The different meanings ascribed to the term acceptance were clarified, and the role acceptance plays in adjustment was explored.
The meaning of adjustment that emerged from the results was presented, as well as three possible dimensions of adjustment that were suggested by the data. The importance of recognizing the idiosyncratic nature of adjustment was emphasized.
CHAPTER 5
DISCUSSION

Overview

This chapter begins by giving a rationale for examining spinal cord injury in relation to transition theory. Transition theory is explained, and spinal cord injury as a type of transition is then described. This is followed by a discussion of its impact on routines, assumptions, roles, and relationships. Factors influencing transition that are particularly relevant to spinal cord injury are identified and discussed. Models of the transition process, as conceptualized by Bridges (1981) and Schlossberg (1995) are outlined. Concerns about the use of such models to aid in understanding transitions in general, and specifically the transition of spinal cord injury, are considered. The chapter closes with a discussion of the implications for research and practice that are suggested by this study.

Adopting a Transition Perspective of Spinal Cord Injury: Rationale

This study approached the phenomenon of spinal cord injury as a lived experience, and as one of the many different ways of life which comprise our world. The results convey a picture of initial upheaval in which the participants' relationships with self and environment were thrown into turmoil by the sudden traumatic event of sustaining a spinal cord injury. What followed was a journey down a path of experience which began at a place where the injured individual felt distinctly out of place in an environment that was often physically and socially difficult to access, in a body with which they suddenly had no familiarity, and with a self-concept that just as suddenly appeared not to be able to co-exist with their changed physical being. From this
starting point, they proceeded along their life paths which took each of them, in his or her own time and own way, to a place of personal "fit" with the environment, their bodies and their sense of self. This is not to say that this sense of "fittingness" is an endpoint to be achieved, and once achieved remains stable and unchanged for all time. The self and environment are in relationship with one another and to some extent, construct one another. Based on the interaction of self and environment, the self-concept is formulated and one conceives of oneself in any number of ways; as a poor athlete, an astute business person, an activist, a spouse, parent, a good, honest member of the community. The degree to which one esteems oneself influences self-concept, and may be considered an important component of it, depending on how salient it is to the person. Environment, self and self-concept are linked together, and given that circumstances may change at any time, the potential for changes in environment, self and self-concept, as well as one's sense of "fit", is constant.

To say that this study has conveyed the message that life goes on for people who have a spinal cord injury is to simplify and minimize what the results demonstrate. The message the participants have sent is exceedingly more important and presents somewhat of a challenge to researchers, health care and rehabilitation practitioners, and society in general. The participants' stories have shown not just that life goes on after injury, but rather, meaningful living goes on. The results of this thesis add to the growing evidence that, in the process of finding their "fit", people with spinal cord injuries allot less and less importance and significance to disability and attribute more and more to constructing the meaningful life they wish to live; a life in which disability is only
one factor (Carpenter, 1991, Miller, 1993, Shontz, 1982, Yoshida, 1991). As well, there is growing recognition that rehabilitation is by no means complete upon discharge from the rehabilitation facility, and far more "on the job" training takes place when individuals find themselves confronted with the everyday realities of living in society outside the artificial microcosm of the rehabilitation centre (Carpenter, 1991, Dew, Lynch, Ernst, & Rosenthal, 1983, Oliver, et al., 1988, Steichele, 1995, Vargo, 1982). Research is showing, as does this study, that after rehabilitation, people with spinal cord injuries, regardless of the level of injury, are able to, and do, go on about the business of living meaningful, satisfying, healthy lives in their communities (Carpenter, 1991, Oliver, et al., 1988, Phillips, 1984, Yoshida, 1991). Evidence is slowly accumulating showing that, in the long-term, disability is not the main concern of people with spinal cord injuries. What is of concern is living a life in which they are able, physically, socially, emotionally and intellectually, to pursue whatever it is, for them, that will bring meaning and fulfillment. Studies which continue to dwell on specific, isolated consequences of injury in the short-term, and which ignore life after rehabilitation are very much at odds with the reality of the lives of people who have a spinal cord injury, for, if nothing else, their lives do go on, not uncommonly all the way into the senior years (Trieschmann, 1992).

Impressive advances have been made in medical and rehabilitation technology, as well as in social awareness, since the days when, for those with spinal cord injuries, life was generally considered not worth living and often did end prematurely due to secondary medical complications. The power of this archaic attitude is attested to
by the fact that it lingers on today, more than half a century later, in a
technological, reasonably socially aware society, in a "personal tragedy"
view of spinal cord injury that emphasizes loss and deficiency. Health
care professionals seem reluctant to dispense with this outlook
(Carpenter, 1991, Oliver, et al., 1988), even though research is showing
it is no longer appropriate. Perhaps this is due, in part, to the fact that
there is no well established theoretical framework to turn to which
offers an alternative conceptualization of spinal cord injury as a life
experience. In order to understand it as an experience of living, it is
necessary to make a radical departure from the medical model which
sees it as a "condition" in need of "treatment", and to frame it as a life
experience that begins with physical trauma which must initially be
treated and stabilized with medical attention, and which then carries
on years afterward. Transition theory was found to be extremely
relevant to the results of this study, and provides an excellent
alternative framework for conceptualizing spinal cord injury. As such,
the research findings will be discussed in relation to it, and in
particular, to the work of Nancy Schlossberg (1981, 1995). Since the
theory of transition describes the experience of living with spinal cord
injury with such remarkable accuracy, it must be noted that my prior
knowledge of it was minimal, and I researched it only after analysis of
the data had been completed and the results had been written. I did
not have the preconceived intention of situating the experience of
living with spinal cord injury within the framework of transition
theory.
Transition Theory

According to Kimmel (1990), "the concept of transition refers to a period of change, growth, and disequilibrium that serves as a kind of bridge between one relatively stable point in life and another relatively stable but different point" (p.104). Transition is a process over time that "results in changed relationships, routines, assumptions, and roles....[and] often requires new patterns of behavior" (Schlossberg, 1995, p. 27-28). It may be linked to one identifiable event or non-event, that is, an anticipated event which does not occur. From this perspective, becoming spinal cord injured is a transition event that sets in motion a transition process. This process involves moving from what Lipman-Blumen (as cited in Schlossberg, 1995) call "pervasiveness", wherein the transition is all-consuming and "permeates all of a person's attitudes and behaviors" (Schlossberg, 1995, p. 36), to "boundedness" wherein it is integrated into one's life and "has become only one of the dimensions of living" (Schlossberg, 1995, p. 36). According to transition theory, a person's subjective interpretation of the transition he or she is going through is what is of importance, rather than the transition event itself. It is recognized that one's reactions to transition will change over time, as the process unfolds and one moves toward boundedness. Furthermore, it is recognized that understanding the transition process "requires the simultaneous analysis of individual characteristics and external occurrences" (Schlossberg, 1981b, p. 3). In response to her colleagues' critiques of her early formulations of the transition model, Schlossberg (1981a) revised the central question the theory seeks to answer. Rather than asking "whether or not one has adapted" (Schlossberg,
1981, p. 50), it instead asks "how a person responded over time to a particular life event" (p. 50). To understand that, is to understand the transition. In the framework of transition theory then, becoming spinal cord injured is a life event that triggers "changes in an individual's perceptions of self and the world" (Schlossberg, 1981, p. 7). It precipitates a process wherein the individual responds to initial and subsequent changes in self, environment, and the relationship between the two. As this process evolves, the pervasiveness of being spinal cord injured diminishes and it becomes only one aspect of life. As the results of this study showed, this is exactly the experience of spinal cord injury that participants described. As well, analysis of participants' thoughts about adjustment led to a conceptualization of it as the course of an individual's response to change. This is virtually identical to the definition of transition put forth in Schlossberg's theory; that is, a process over time that results in change and can only be understood in terms of the individual's response to such change. My research demonstrated that when people with spinal cord injuries were given the opportunity to describe, from their perspectives, the entirety of their experience, they described their involvement in a process of transition. The remainder of this chapter provides an in depth discussion of this transition, beginning with identification of the type of transition it is, and a description of the impact it has on an individual's life.

**Spinal Cord Injury: An Unanticipated Transition**

As opposed to an anticipated transition that is expected and predicted, or a non-event transition that is expected but does not occur, spinal cord injury is an unanticipated transition that is not scheduled
and not predicted. As is common to unanticipated transitions, it involves crisis, which is defined as a "severely upsetting situation of limited duration" (Schlossberg, 1981, p. 6). In addition to occurring unexpectedly, onset is sudden, the affect associated with it is, of course, negative, and the source is external, meaning change is forced upon an individual by circumstances. All these features serve to increase the stress of the transition.

**Impact**

According to transition theory, it is not the transition event that is most important, but the impact it has on an individual's life (Schlossberg, 1987, 1995). The transition of spinal cord injury can be further elucidated through examination of the way in which it affects a person's, routines, assumptions, relationships and roles. Crises such as spinal cord injury have the effect of immediately interrupting an individual's routines. The disruption will last until the danger associated with the crisis has passed, and the person has either resumed former routines or settled into different ones. The event of spinal cord injury effectively removes a person from all their familiar life routines for a considerable length of time. A person no longer gets up and goes to work everyday, no longer picks up the children from school every afternoon, no longer plays hockey every Wednesday night, and so on. Home, work and leisure routines are all drastically affected.

Once the injury has been stabilized and individuals are no longer medically at risk, they enter rehabilitation where they become involved in a routine that is dictated by both the operational structure of the institution, and their particular programs, which, this study
found, concentrate mainly on physicality. Other research supports this finding (Carpenter, 1991, Oliver, et al., 1988, Steichele, 1995, Whalley-Hammell, 1992, Yoshida, 1991). When people are discharged, the routine to which they have become accustomed is left behind. In rehabilitation, they are in an environment that is disconnected from the outside world, and there is little recognition of the routines that were associated with their lives in the community. The separation between rehabilitation and the community is evidenced by inadequate preparation before discharge for establishing new routines in community life, and a lack of ongoing support in doing so once community living begins. This separation is well documented in the literature (Dew, et al., 1983, Carpenter, 1991, Cogswell, 1984, Oliver, et al., 1988, Steichele, 1995, Vargo, 1982, Yoshida, 1991). McColl, Hei and Skinner (1995) refer to the crisis of community readjustment, and the present study found that entering the community was a difficult, negative experience, and without a routine or even an idea of one that went beyond the physical routine of getting up, getting dressed, and so on, participants coasted, or to use their words, they "didn't do a lot" and "vegged out". Cogswell (1984) found that once individuals were back in the community after being immersed in the rehabilitation routine, "days often seemed wasted and empty and appeared to lead nowhere" (p. 162). She identified this as a time of social isolation and inactivity. Steichele's (1995) study revealed that one of the stressors in the experience of spinal cord injury was going from a highly structured routine in rehabilitation to having no routine in the community. As her research points out, and as was evident in this study, this can have
destructive consequences such as drug and alcohol abuse, and is a concern that needs to be addressed.

When spinal cord injury is viewed from a transition perspective, which involves concurrent analysis of self and environment, it becomes clear that the problem is not just that people have no routine, but they are struggling with issues of identity at the same time. My research points out that upon return to the community, people find themselves wrestling with uncertainty about self-identity. Studies by Carpenter (1991), Cogswell (1984), and Yoshida (1991) found similar results. A more thorough discussion of this uncertainty will follow when the effect of spinal cord injury on roles is considered. It seems apparent, however, that easing the stress associated with returning to the community will require a complex plan of intervention that recognizes many influential factors such as issues of self-identity, resources, supports and experience.

The transition of spinal cord injury affects an individual's assumptions about the world, one's life, and one's self. At the deepest philosophical level, the occurrence of spinal cord injury may cause a person to lose their "trust in the universe", as one participant of this study put it, and challenge assumptions about fate and one's power to direct one's life. At a more practical level it brings into question assumptions about the present and future which have been formulated, in large part, according to one's sense of self and one's abilities pre-injury. This study found that after injury, peoples' self-identities are greatly disrupted, as are their perceptions of their abilities. As such, assumptions are also disrupted. In terms of self, pre-injury assumptions about the roles one will enact in life may be
challenged. Again, this is explored in detail in the discussion of role change which follows.

Assumptions about abilities pertaining to anything from going out and buying a pair of shoes to having a child may be affected by spinal cord injury. This study indicated that after injury, individuals did not know what they were capable of doing, or what they would be capable of doing in the future. They were in a position where old assumptions were cast in doubt and new ones could not yet be constructed due to a lack of experience in the new situation. As experience is gained in rehabilitation and the community, and one's sense of self becomes restabilized, old assumptions are discarded if no longer appropriate and new ones are formulated. It seems that the strategy of pursuing options is principled according to a general assumption that a way can be found to meet a goal. The pursuit of options reflects an ongoing process of testing assumptions and building a set of new ones that are congruent with life circumstances. It makes sense that individuals who live according to assumptions that are in keeping with their situation will be able to move forward more easily than those who are having difficulty abandoning those that are no longer appropriate. This highlights the need for people to accept their situation, in the sense of recognizing and being fully cognizant of it, in order to move ahead. This was a need identified in this research as well as in studies by Carpenter (1991) and Yoshida (1991). It must also be pointed out that new assumptions may be derived from a negative outlook on the situation or an overly optimistic one, and as such are not likely to be beneficial. Transition theory recognizes,
however, that assumptions may be continually revised as the transition process evolves and changes.

Assumptions are not only affected by disruptions to sense of self and to perception of abilities. At a more fundamental level, they are affected by people's relationships with the environment. The relationships individuals have with their social and physical worlds before they are injured are premised on various assumptions. These are in large part assumptions about physical and social access. Injury changes the relationship because it can no longer be premised on the same assumptions. Physical and social access can no longer be assumed, certainly not to the extent they were pre-injury. This is acknowledged in the literature (Oliver, 1981, Quigley, 1995, Steichele, 1995, Trieschmann, 1992) and was evident in this study in descriptions of the physical obstacles people encountered upon returning to the community, as well as the uncomfortable social environment they came upon. After injury, a person is in a different relationship with the world and discovers old assumptions about physical and social access must be revised. While it is true that individuals may assume the right to access, the reality of the physical and social environments is such that it is not always afforded.

The preceding discussion of how spinal cord injury affects a person's routines and assumptions provides some insight into the impact it has on relationships. A person's relationships with the environment, with others and with oneself are all affected. As stated, the relationship with the environment changes dramatically after injury. The physical and social worlds cannot be accessed and negotiated the same way they were before injury. A person's
relationship with the world is largely perceived in terms of physical and social interaction with the environment, and it follows that when one's contact with the environment is altered, so too is one's relationship with it. It seems reasonable to suggest that the impact of the transition on peoples' relationships with their environments will depend in part on how interactive they were with it pre-injury. A person who was a highly active outdoorsperson and traveler may be affected much more than someone who led a sedentary lifestyle, for instance. This underscores the importance of understanding the transition from each individual's perspective, if support and assistance in responding to it are to be effective.

For people with spinal cord injuries, personal relationships are put under considerable strain due to the fact that the transition begins with crisis, as well as the fact that it has a massive impact and touches every aspect of a person's life. Evidence of this strain was abundant in this research, with 80 percent of participants mentioning at least one instance when a relationship became stressed. Close relationships with parents, siblings, spouses or close friends were affected, and often the strain culminated in serious breakdown or termination of the relationship. Cogswell (1984) has also noted the negative impact of spinal cord injury on relationships. The effect can also ultimately be positive, and relationships can be deepened, as shown in the present study by one participant who had the positive experience of "really getting to know his father" after his injury.

It is interesting to speculate about what other factors influence the effect the transition has on relationships. The fact that the individual is absent from many relationships at home, work and play
causes strain in itself. Suddenly the person is no longer an active participant in the relationship. Furthermore, the absence may be prolonged. The depth of the relationship and the intensity of the feelings associated with it is likely influential, as suggested above. It does not necessarily follow that relationships that have a high emotional investment will endure and those that are more superficial will erode. Others, be they close friends, relatives, or acquaintances, may experience feelings of fear and helplessness that may be overwhelming and cause withdrawal. The injured individual's self-identity may become destabilized, and as shown in this research, this may lead to social withdrawal and a reluctance to engage in relationships.

It seems that role disruption after spinal cord injury can significantly impact relationships. When injured individuals are no longer actively present in their relationships, they are not seen to be fulfilling their roles in them and they may become disconnected from them in this way, by themselves as well as others. Further, an individual's own experience of role confusion may make it difficult, or even impossible, to function in pre-injury roles, even when he or she is no longer absent. This change in roles adds strain to relationships in that they have been structured around certain roles being enacted by each person involved. Role change is one of the factors that Schlossberg (1995) identifies as influencing transition, and because it's influence is so strong, and it can affect not only one's relationships, but one's routines and assumptions as well, it is discussed in depth below, along with other factors that are particularly salient to the transition process of spinal cord injury.
Factors that Influence the Transition of Spinal Cord Injury

Role Change

The findings of this study suggest that people with spinal cord injuries may go through a series of role disruptions and changes as they move through the transition. After the initial phase of disorientation when participants became aware of the physical changes that had resulted from their injuries, one reaction was to question their role status. They were no longer certain of what they were capable of doing, and considering Merton's definition of role as the "behavioral enacting of the patterned expectations attributed to a position" (as cited in Schlossberg, 1995), it follows that they were no longer certain of their roles. This role confusion can only be sorted out with time and experience, and it would seem a logical proposition that the greater the degree of satisfaction and comfort individuals have in the roles they see themselves playing, the more the transition has been integrated into their lives. As participants began to interact socially and learn about their physical capabilities, first in rehabilitation and then out in the community, they learned through experience which roles still fit, and which did not. Considering roles are conceptualized according to the behaviors enacted in carrying them out, if those behaviors can no longer be enacted because of the physical consequences of injury, the roles will no longer seem to fit. This study found that in rehabilitation, the primary focus is on physicality, and as other research has shown (Carpenter, 1991, Steichele, 1995, Yoshida, 1991), the pervasiveness of disability is reinforced. During the rehabilitation phase of their experience, people who have spinal cord injuries are confronted daily with their inability to physically behave in many roles in the way they
are accustomed, and therefore, these roles seem to no longer fit.

People identify with a role not only physically, but socially and emotionally as well; however, we are present in the world first and foremost physically. The basis of the contact we make with the world, and of our interaction with our environments, is physical, by virtue of the plain fact that we are physical beings. Via our physicality, we make social and emotional contact, and are socially and emotionally interactive. Thus the inability to physically behave in a role in the manner in which a person is accustomed, gives rise to a perception of lack of fit that may well include the social and emotional ways of being in that role. When the body no longer responds to a person's commands to move so that one can carry out the behaviors associated with a role, the social and emotional fit of that role is likely put into question as well. Understandably one wonders: "How will I be, or how do I continue to be, a partner, a parent, a lover, a worker, and so on?"

The clash between identifying with a role based largely, but not entirely, on physical experience pre-injury, and no longer being able to carry out the physical behaviors associated with it post-injury, is similar to what Carpenter (1991) called the experiential split. In her research she found that the inner experience of self, which she describes as consisting of "mind, character, emotions, conscience and aspirations" (p. 83), stays the same as it was before injury, but it is "firmly rooted in the able-bodied normality" (p. 83) which has changed. "The disability and overall sense of loss are initially symbolized by the physical changes or the external experience of the disability," she says, [and] "these are separate from the internal concept of 'self' which remains essentially unchanged" (p. 83). Her findings also indicated,
however, that after injury a "sense of loss of self" (p. 84) was experienced. This is in agreement with the results of this research which showed a connection with core self remained after injury, but became destabilized initially, when participants felt unsure about their identities. Yoshida (1991) found similar results, although her conception of continuity of self is broader than mine, in that it includes both core and peripheral aspects of self. She distinguished between the non-disabled and disabled selves in her work, and found that the non-disabled self was sustained after injury. The nondisabled, or former, self consists of core and peripheral aspects of self. Core aspects of self, in her definition, are the conceptions of self that the individual considers essential to who he or she is. Peripheral aspects of self, on the other hand, are not considered by the individual to be important. She suggests that continuity of self involves the individual's assessment of whether essential, or core, aspects of self are compatible with the disabled self. Compatibility is assessed according to "whether the physical self...can engage in the essential self....." (p. 93). Integration of the non-disabled and disabled selves "is a process of recovery of lost aspects of the non-disabled self" (p. 88). Just as the present study showed that restabilization of identity came about as participants navigated their passage through the phases of experience, and thereby gained experience, Yoshida (1991) found that integration was "firmly grounded in the experiencing of learning" (p. 89). Similarly, Carpenter (1991) found that people with spinal cord injuries engaged in a complex learning process "associated with a gradual build-up of a new framework of experience" (p. 84) which facilitated resolution of the experiential split.
As has been mentioned, this study found that the rehabilitation environment is far removed from the 'real world reality', and other research has produced similar findings (Carpenter, 1991, Dew, et al., 1983, Oliver, et al., 1988, Steichele, 1995, Yoshida, 1991) As such, real life roles, such as spouse, parent, business partner, and so on, are not truly confronted until an individual has left rehabilitation and is in the real life experience. Entrance into the community, and the resumption of real life, was found to be a stressful experience for which people were ill-prepared. The fostering of dependency in the rehabilitation setting has been well documented in the literature (Carpenter, 1991, Steichele, 1995, Trieschmann, 1992, 1989, Yoshida, 1991) and was evident in this study in participants' comments that the rehabilitation centre was a place where someone was there, "holding their hand"; where they were "coddled"; and where leaving was hard and like "leaving the womb". It seems that this dependency serves to heighten the stress associated with moving on into the community.

People with spinal cord injuries are in a position, at least initially, of literally not knowing how to take care of themselves. While they are in the process of learning how to do that, the rehabilitation environment is perceived as a place of safety where help is at hand should anything go wrong. At the same time, it is an environment that exacerbates any confusion there may be about one's role as an adult. People who have a spinal cord injury are suddenly catapulted from a world in which they conduct themselves as self-determining adults, into a situation in which they often feel childlike. In addition to this being evident in the references to leaving the womb and having one's hand held mentioned earlier, it was also apparent in phrases such as
"you learn how to crawl before you learn to walk", and "it's like growing up all over again" which participants chose to describe their experiences. Depending on the level of physical function after injury, there is an accompanying loss of ability to carry out certain tasks. For those who can no longer perform the tasks that are mastered in childhood, especially those that are recognized as signifying a child's burgeoning independence and autonomy, such as feeding oneself and controlling one's bodily functions, feelings of childishness may be particularly accentuated. As pointed out earlier, the emphasis in rehabilitation is on physical training and skill acquisition which is centred mainly around mastering what are referred to as "activities of daily living". This is not entirely accurate, and an important clarification needs to be made. This study and others (Carpenter, 1991, Oliver, et al., 1988, Steichele, 1995) support the contention that it is the physical mastery of the "basic activities of daily living" that are being taught in rehabilitation programs. These are concerned primarily with mobility and what is referred to as "self-care". This term is inaccurate as well, with the focus in rehabilitation being mainly on "physical self-care". The primary goal is to equip people to the greatest extent possible with physical skills that will allow them to be mobile and to keep clean, clothed and fed. Rehabilitation, with its strong physical orientation, teaches people who have a spinal cord injury to become as accomplished as possible at the skill level of a child, and then declares them ready to reenter their adult worlds. While mastery of the basic activities of daily living is a perfectly reasonable goal for those who have the capability, the emphasis on physical ability and skill is far too narrow and addresses only one dimension of living. For people who
work, going to work each day is an activity of daily living. For those who are partnered, functioning in their relationships is an activity of daily living. For those who are raising children, parenting is an activity of daily living. These adult activities requiring physical and social skills at an adult's skill level are largely overlooked. Before their return to the community, then, people with spinal cord injuries often experience feeling like children due to changes in physical functioning and ability. This is reinforced by a rehabilitation program that emphasizes a child's skill level and the accomplishment of the basic skills of living ordinarily learned in early childhood. Furthermore, the rehabilitation environment is safe and protected, which in itself fosters dependency. It is not at all surprising that, as this study and many others found (Carpenter, 1991, Cogswell, 1968, Oliver, et al., 1988, Steichele, 1995, Vargo, 1982, Yoshida, 1991), individuals were not prepared for return to their lives in the community where they were confronted with their roles as partners, wage earners, parents, and so on.

**Duration**

Another factor that influences the transition of spinal cord injury is duration. Whether or not a transition is perceived as wanted or unwanted, and whether the change it brings is permanent or temporary influences one's reaction to it. The reaction to a desired change that is not going to last long will be different than reaction to desired change that is perceived as permanent. Reaction to an unwanted, but temporary, change is going to be different than the reaction to unwanted, permanent change. Schlossberg (1981b) suggests that transitions of uncertain duration are the most stressful.
In terms of spinal cord injury, the transition is unwanted and is currently viewed as permanent, in that there is no known way to repair the damaged spinal cord. It is more precise, however, to say it is currently beginning to be viewed as potentially temporary as medical research advances and new discoveries are made. The conviction that no medical intervention will ever be available to repair damage to the spinal cord, and thus that there is no hope of restoring function, is just beginning to be challenged within the medical research community.

**Uncertainty.**

It seems that uncertainty about duration can easily be overlooked as a factor that adds to the difficulty of the transition because traditionally spinal cord injury has been viewed as a condition. From this perspective, the condition is seen as permanent and there is no uncertainty as to whether or not it will endure. As a transition however, it is understood as a process over time that is characterized by change and disequilibrium. This perspective brings to light the fact that people with spinal cord injuries do grapple with considerable uncertainty about duration as they progress through their experiences. Expected return of motor and sensory function, according to medical diagnosis and prognosis, is not always certain. Although some kind of permanent change in function will occur as a result of injury, the ultimate nature and degree of that change is not immediately known. Although medical technology allows for a high degree of accuracy in the prediction of return, it is not absolutely accurate, as was true for one of the participants in this study who gained more than was anticipated. At the outset, an individual does not know absolutely how
much natural healing will occur and is therefore not certain about how much function will naturally be restored. In rehabilitation, uncertainty about function continues after healing is complete, and motor and sensory return has reached a plateau. During rehabilitation, people are primarily concerned with exploring and testing the limits of their functional ability as they continue to gain strength and become familiar with their bodies, and as they learn ways and means of compensating for lack of natural function.

Underlying the uncertainty people with spinal cord injuries face about natural return of function and about the extent to which they will be able to compensate for lack of function, is a frightening uncertainty about what their capabilities will be. Physical capability changes as physical function changes, but participants of this study showed that predictions of capability based on a level of physical function are not necessarily accurate. In fact, not believing such predictions was seen as an important element of the strategy of pursuing options which they used to navigate their passages through their experiences. While physical return does plateau and remain stable once the body's natural healing response is complete, changes in capability extend as far into time and as far into the imagination as a person is willing to go, and are not confined to the physical realm, but stretch into the social, emotional and intellectual corners of a person's life. To use an example from this study, after his injury Dan was uncertain as to what he was generally capable of doing. At the time of his interview, long after his physical return had stabilized, he had discovered he was capable of returning to school, retraining and competing in the labour market. He was still uncertain as to whether
or not he would be capable of being in a relationship. At some point in the future he may have discovered that he is and find himself wrestling with uncertainty about raising a family.

Uncertainty and coasting.

As individuals going through the transition of spinal cord injury move toward boundedness and situate disability among the many aspects of their lives, uncertainty becomes related less to disability and more to life dilemmas that all people inevitably encounter. It may be that in rehabilitation, with the emphasis on physical ability and the lack of connection between life in the rehabilitation centre and life in the community, that uncertainty is fairly contained and is concentrated predominantly on physical function and ability. Once a person goes back to the 'real' world where physicality is taken for granted and one's ability to operate in the social world is much more relevant, uncertainty may very likely expand into all realms of experience. The coasting phase of the experience usually began at the same time individuals returned to their communities and may have reflected an immobilizing uncertainty about what their physical and social capabilities were in the real world. Once back in the community, people with spinal cord injuries are faced with refamiliarizing themselves with the physical environment and learning how to get around in it, as well as with how to interact in the social environment. Uncertainty about their capabilities in both these domains may leave them not knowing how to proceed with their lives. Cogswell (1984) agrees with this hypothesis. It is interesting to note that the two participants of this study who did not begin a period of coasting as soon as they returned to the community had specific goals they wanted
to pursue. Once these were abandoned or achieved, having no other express goals, a period of coasting ensued. This is not to suggest that it would therefore be advantageous to assist people with spinal cord injuries, before leaving rehabilitation, to identify goals they wish to pursue upon returning to their communities in order to avoid the 'problem' of coasting. Considering that spinal cord injury is a massive transition, it may, in fact, be that the coasting period is an important restorative part of the experience during which an individual may pause and reenergize, while assimilating the experience thus far and contemplating the future. On the other hand, the coasting phase can be prolonged and characterized by destructive behavior. Even in such a case, the experience of being self-destructive may be what sets the person on a positive course. It seems that, as transition theory advocates, each individual's experience must be understood from his or her perspective in order to ensure that interventions and supports are timely, appropriate and effective.

Overcoming uncertainty: hope.

The transition of spinal cord injury is a process that does involve a great deal of uncertainty, especially in the early years, which raises the question of how people overcome the uncertainty and forge ahead in spite of it. Hickey (1986) says that "just a glimmer of hope...commits one to purpose and to action" (p. 134). In order for forward movement to be maintained, she says, "there must be hope" (p. 134). This study, as well as research done by Laskiwski and Morse (1993), and Morse and Doberneck (1995) demonstrates that hope plays a crucial role in the response to spinal cord injury. Hope was particularly evident in this study in the general increase in positive attitude when individuals
moved from acute care to rehabilitation. During the disorientation phase when people were still in hospital, they often had difficulty understanding their situation, and could not imagine what was possible and what the future might look like. For some, it seemed there was no possibility, and without hope they had thoughts of suicide. In the rehabilitation environment, possibility was discovered through contact with others in a similar situation, as well as by learning from them and from trained professionals. It seems the discovery of possibility fortified, or, for some, actually ignited, hope, and people did commit to a purpose and to action and began to move forward toward regaining as much physical independence as possible.

Evidence of hope in this study is perhaps strongest in the strategy of pursuing options that was identified as being useful to participants in helping them move forward through their experiences. This involves having an attitude of openness to other options as well as a willingness to seek alternative ways to move toward achieving one's goals. This strategy was used extensively throughout people's experiences in the achievement of physical tasks as well as larger life goals. While it is clear that the discovery of possibility sparked or strengthened hope, the relationship between using a strategy of pursuing options and the maintenance of hope is less straightforward. As long as a glimmer of a possibility existed that doing something differently would result in a goal being reached, no matter how minuscule or complicated the alteration might be, individuals sought and pursued options, indicating they had hope their goal could be achieved. Efforts to realize a goal can be exhaustive as well as exhausting, and an interesting question worthy of further investigation
is "What sustains the motivation to keep pursuing options?" If it is hope, what sustains the hope? Does hope sustain the motivation to pursue options or does the pursuit of options sustain hope? Do they sustain each other, and if so, how? This study found that people with spinal cord injuries find themselves in an unfamiliar situation in which they no longer know what is possible, and the discovery of possibility and the pursuit of possibility were critical to being able to move forward through uncertainty. It seems that hope is even more critical, if it is not the most essential factor, for possibility without hope is not really possibility at all.

The identification of a critical turning point as one phase of the experience of living with spinal cord injury was one of the most surprising and interesting findings of this research. Povolny, et al. (1993) briefly mention a turning point linked to a specific event that was experienced by both of the women in their study. Other than this, it seems that no similar results have been reported in the literature. The critical turning point was always associated with a low point in the experience and, for some it was considered the lowest point. It was, it seems, a time when hope was in danger of fading away completely. What is intriguing is that not only were individuals who were going through this phase able grasp enough hope to make a decision to take action to get back on a positive course, it was apparent that the resurgence of hope was so strong it carried them into a future which they were able to see as being rich in possibility. In fact, this time was spoken of as being when "life started", when individuals "got back into life" and when all of life lay ahead of them and they could do whatever they wanted to with it. This point in the experience deserves serious
attention for at least two important reasons. Firstly, this can be a time of existential crisis when people find themselves assessing their lives in terms of worth. They are on a life course that forces them to choose between taking control and affirming the value of their lives, or surrendering to circumstances, personal and situational, that reinforce the devaluation of life. They are confronted with accepting or rejecting the belief that their lives have no value, and with a choice between hopelessness and hope. It is perhaps precisely because at this point there are no apparent choices other than hope or deepening despair, that people are compelled to embrace hope and "get back into life."

When an individual goes through the critical turning point, the choice that is made can have life or death consequences. If for no other reason than that, it needs to be well understood, in the context of the person's experience.

Secondly, the critical turning point is a very difficult, upsetting and unpleasant time for people, but it seems it may also be a necessary and ultimately beneficial part of the experience in that it was a time when people took responsibility for their lives and moved ahead with restored optimism. It may be that visiting despair and having an opportunity to look into a hopeless future is the catalyst for grasping onto hope and being able to envision and pursue a future of possibility.

It may be that efforts to circumvent this time are not necessarily warranted, but rather it seems more appropriate that it is understood well so that people can be supported effectively as they go through it. Further research is needed to corroborate the existence of a critical turning point and to delineate the features of it and the dynamics involved in going through it. Transition theory offers little to help
explain the critical turning point, although Kimmel (1990) does point out that transition may involve a personal turning point.

**Concurrent Stress**

A true appreciation of the transition of spinal cord injury is not possible without consideration of any concurrent stress an individual may be experiencing. This study found ample evidence that highly stressful events are commonly associated with spinal cord injury, and often they are transitions as well. They include termination of significant relationships, loss of livelihood, loss of one's home, serious health concerns, and death of a significant other. Spinal cord injury is a transition event that is very likely to be quickly followed by at least one unanticipated transition event, and/or non-event transition. These "secondary" transitions are part of the transition of spinal cord injury and will most certainly influence an individual's reactions to it. As such, in order for spinal cord injury to be understood, it is crucial that all stressful events and secondary transitions connected to it be understood as well.

It is important to emphasize here that it is not sufficient to restrict assessment of these events and transitions to the first one or two years post-injury. Transition theory offers a much broader framework for understanding spinal cord injury than does the medical model, but despite the focus on individuality, the temptation to put a time limit on the process of transition persists. Even Schlossberg (1995) suggests a maximum of two years as the time needed to fully move through a major transition. In my opinion this unnecessarily "medicalizes" the theory and seems incongruent with it. This study showed it may take much longer than two years, depending on the
individual. Oliver, et al. (1988) had similar findings in their study. Introducing a time-frame for transition allows one's process to be pathologized when it does not conform to that time-frame. In working with individuals from a transition perspective, it seems it would be more effective to respect their processes and to detect and be alert to signals indicating they are stuck. Attempting to push people to a point they are not confident or comfortable with likely means they are not yet ready to move there. They have not reached that point in their transition, and as this study found, such effort will be wasted and this "help" will be rejected, sometimes vehemently. Understanding transition, then, requires understanding of the whole process, whether it takes two years or ten years. The additional stressful events and the non-events a person experiences may seem to occur predominantly within the first two years of injury and are often negative. It is important to recognize that positive and negative events and non-events occur throughout the transition and must be assessed accordingly. It is also necessary to understand an individual's changing reactions to the transition as it unfolds. It cannot be assumed that the reaction to an event that happens one year after injury will be the same if a similar event occurs again five years later.

Support

This study indicated that support is an important factor influencing the transition of spinal cord injury. From a transition perspective, it is essential to understand the individual's perceptions of the supports available to him or her throughout the transition. Not only will the need for certain types of support fluctuate through the experience, depending on the circumstances at any given point, but so
too might a person's responses to it. Research by McColl, et al. (1995) suggests perceptions of specific types of support are subject to change over time. Understanding support in the framework of transition may help alleviate frustration that may be encountered when it is rejected. It may also diminish the tendency to pathologize the individual's "problem" behavior when support is not met with a favorable response.

House (as cited in McColl, et al.), proposes three types of support that were identified in the current study. The first of these is instrumental, which involves "the efforts of other people and...[includes] practical supportive behaviors such as giving [someone] a drive somewhere" (p. 396). This is very similar to the type of support I named accompaniment, but does not specify that it be emotionally beneficial. The remaining two types House suggests are informational and emotional support. Informational support is typically linked with professionals and formal sources such as community and government agencies, and service providers. Considering the disconnection between rehabilitation and community life, it was not surprising that such support did not appear to play a key role in peoples' experiences. Only cursory mention was made of it in this study, and other research has found it to be unsatisfactory (Oliver, et al., 1988, Steichele, 1995). Steichele's results showed that informational support was commonly considered inadequate, invasive and bureaucratic, and resulted in people feeling unduly stressed, rather than supported. While support from formal sources did not emerge as an important aspect of the experience in the present research, it was evident that informational support did come from others who shared similar circumstances. Being supported in this way
by people who had first hand experience was seen to be very important and was highly valued, both in rehabilitation and the community. This peer support was also recognized in research by Carpenter (1991), Steichele (1995) and Yoshida (1991). It would seem that this support is worthy of consideration as a component of any programs that may be developed to address the discontinuity between rehabilitation and community living, and the difficulties associated with the return to the community.

Schlossberg (1995) recognizes informational support that comes from institutions and community organizations as one of four types. The other three, which she classifies according to their sources are, support from intimate relationships, which involves trust, understanding and sharing confidences, support from the family unit, and support from one's network of friends. This study identified family and friends as the primary providers of support, and the importance of being supported by them was clear. While intimate relationships were not found to be a distinct type of support, intimacy was shown to be a quality of many of the relationships that were supportive, and especially of those that were emotionally supportive.

The results of this study suggest that in finding affiliation with others, individuals have the opportunity to develop relationships which are grounded in a special intimacy that is created largely by the situation. Association with peers, both in rehabilitation and the community, was valued because a trust existed that such people had a genuine understanding of the situation. I would propose that this understanding goes far deeper than the immediate circumstances, and encompasses the impact spinal cord injury has had on a person's life.
This seemed evident in the empathy people communicated when referring to others who had a higher degree of physical limitation. Friendly competition among people with different physical abilities was found to be encouraging in rehabilitation, and as one participant pointed out, those who engaged in it were sensitive and careful that they "never put another person down." While this study did not clearly show that people with spinal cord injuries shared confidences, it suggested this was the case. It was evident that they provided informational, as well as emotional support to each other. As one participant said "you're down one day, but you're surrounded by everyone else in the same position, so they pick you up...and the next day they're down and you lift them up." It seems highly likely that this mutual exchange of support involved the sharing of confidences. Finding affiliation has been recognized as an important aspect of the experience of living with spinal cord injury by many authors (Carpenter, 1991, Cogswell, 1984, Laskiowski, & Morse, 1993, Steichele, 1995, Yoshida, 1991). It would seem that the importance of affiliation with others in a similar situation is not simply that it provides a good resource, or that it provides emotional support, but rather it lies in the fact that the affiliation is built on a foundation of trusted understanding. This is very instructive and emphasizes the necessity of understanding the individual's perspective in the provision of support.

The findings of the present study showed that emotional support was provided to people with spinal cord injuries by others who were in a similar situation, by friends, and by family. It was evident that injured individuals turned to close friends and family to "share the
hard times with", and this is perhaps reflective of a different intimacy that existed in these relationships. Whereas the intimacy between people who share the experience of spinal cord injury largely grows out of the situation, the intimacy between injured individuals and their families and friends grows from a mutual understanding of one another. It seems likely that "talking with a friend when times were down" or "sharing the hard times", involved communicating to another one's emotional experience of down times and hard times. Thus, the sharing of how one is experiencing hard times may very well include the sharing of emotional pain. It makes sense then, that people chose to talk with those who knew them and understood them best. These were people who they believed they "could say anything to", who would "stay when you're being a jerk", and who "would always be there". In other words, they were people with whom they had a solid, secure relationship, and with whom they believed they could be themselves. In these relationships there appeared to be a trusted understanding that a person was understood and was accepted for who he or she was. Whereas knowledge of the situation allowed other people with spinal cord injuries to respond with empathy, knowledge of the person allowed family and friends to do the same. Persons who are brought together by common circumstances may find that intimacy stemming mainly from the situation expands as a more personal relationship develops and they get to know one another. This study indicated that enduring friendships among people with spinal cord injuries often began in rehabilitation or grew from contacts made upon return to the community. It also would seem that friends and family
would gain a greater understanding of the situation through their daily life interactions with the person who has a spinal cord injury.

An interesting finding of this study was that receiving a reflection of self from another appeared to affirm and strengthen an injured person's connection to self. It was clear that close friends and family understood the person who had a spinal cord injury for who he or she was, and that injury did not affect this. It would seem then, that such people are perhaps best able to provide reflections of self. Yoshida (1991) suggests that supportive intimates do bolster the injured person's sense of self and that when people with spinal cord injuries are seen and treated no differently than they were before injury, continuity with the "former" or core self is preserved. This study showed more evidence of reflections of self that resulted from new relationships than it did reflections from family and friends. It is possible that in the recounting of their experiences, reflections of self from close friends and family were considered "a given" by the participants, due to the enduring emotional bonds of family and friendship, and the nature of intimacy in these relationships. Without minimizing the importance of reflections from close friends and family, it seems that receiving a reflection of self from a person an individual has come to know after his or her injury provides a strong affirmation of self, and may be equally or even more influential in the process of connecting to self than are reflections from family and friends. Carpenter (1991), Steichele (1995) and Yoshida (1991) have also found reflections of self to be an important aspect of the experience.

Much of the research on social support and spinal cord injury has focused on outcome, in terms of how social support relates to well
being, levels of depression, psychosocial impairment, and so on (Decker, & Schulz, 1985, Elliott, Herrick, Witty, Godshall, & Spruell, 1992a, Elliott, Herrick, Witty, Godshall, & Spruell, 1992b). Some studies have recognized that social support and individuals' responses to it change over time as the experience of spinal cord injury evolves (Elliott, et al., 1992a, McColl, et al., 1995). It seems, however, that more research is needed to understand the dynamics of support as well as the dynamics of supportive relationships, and how both function throughout the changing experience.

Self Efficacy

Self efficacy is a factor influencing transitions that is especially relevant to spinal cord injury. Individuals are said to possess self efficacy to the extent that they believe they have the "capabilities to exercise control over their own motivations and behaviors, and over environmental demands" (Schlossberg, 1995, p. 64). As said earlier, the event of spinal cord injury is not predicted, and because it has such huge ramifications, the apparent randomness of it may be particularly striking. As such, it has the potential to affect a person's sense of self-efficacy at a profound level. There is no doubt self-efficacy is affected. As this study showed, in the disorientation phase, people with spinal cord injuries suddenly find themselves in a position where they are no longer able to cause desired events to occur, by virtue of physical and situational limitations. The physical consequences of injury may make it impossible to carry out desired behaviors in order to achieve a certain outcome. As well, other studies (Carpenter, 1991, Steichele, 1995) have shown that, as the present research suggests, institutions discourage self-determination, thus making it difficult for people to
carry out actions that are perhaps more administrative than physical, in order to effect a desired outcome. It was evident that individuals' sense of self-efficacy was severely affected during the disorientation phase, and they had no idea of what they were capable of doing, or of what they would be capable of in the future.

It seems that in rehabilitation, as people find affiliation with others and begin to discover their physical and social capabilities, self-efficacy strengthens, and there is an accompanying increase in optimism. People begin to discover that they can, in fact, direct their behaviors and achieve intended outcomes. This study showed that in the rehabilitation environment, people discovered possibility and began to test the limits of possibility in terms of their physical abilities. As people became more familiar with their physical beings and gained mastery over various tasks, it seems reasonable to assume that their sense of self-efficacy increased accordingly. Considering the evidence in this study demonstrating the difficulties associated with returning to the community, it is also reasonable to speculate that a person's sense of self-efficacy diminishes when he or she is discharged from rehabilitation and enters into community living, and in fact, other research has shown this to be true (Craig, et al., 1994). Due to the physical differences between the accessible rehabilitation facility and individuals' communities, physical rehabilitation outside the institution continues as people adapt to the demands of their home environments. In addition to meeting unforeseen physical obstacles, which may include anything from a detached garage in the dead of winter to an isolated rural home, when people return to their communities they are confronted with the whole realm of adult social experience. As this
research showed, rehabilitation does not devote adequate attention to preparing individuals to meet the demands of the adult social world. In addition to possibly experiencing role confusion, people may also be unaware of community resources that may be helpful to them. It seems that experience in rehabilitation helps to restore belief in one's physical self efficacy, while positive experiences in the community lead to self-efficacy in the social realm. This was evident in the present research in the rediscovery of the competent self, which was invariably linked to social interaction in the community, most notably in a work setting.

The critical turning point of the experience was a time when people actively took control of the situation they were in in order to turn it around. This represents a determination to fully embrace one's power to direct one's motivations and behaviors to achieve a desired outcome. The creativity of the means some people used in order to get back on a positive track at the critical turning point, and the remarkable courage it often took, are indicators of a fully restored sense of self-efficacy. Schlossberg (1995) states that "self-efficacy enables a person to tackle a new problem with an optimistic expectation that it will be solvable" (p. 97). This is the basis of the strategy of pursuing options. It is interesting to note that after the critical turning point, the strategy seemed to be applied more to the pursuit of larger life goals such as finding a vocation or beginning a relationship, than on accomplishing everyday tasks.

It seems that from the standpoint of the medical model, self-efficacy is strongly linked to an individual's ability to be physically independent. This study gave evidence that people with insufficient
physical potential were not considered good candidates for rehabilitation, although recent research suggests this attitude is changing (Steichele, 1995). Looking at spinal cord injury in the framework of transition provides an opportunity to consider a different perspective of self-efficacy which challenges the notion that it is dependent on physical ability. As stated, self-efficacy involves exercising control over one's motivations, behaviors and the demands of one's environment. It involves the belief that one can cause a desired event to occur, and that one can organize and carry out the necessary courses of behavior to achieve an outcome. Self-efficacy need not have anything to do with physical ability, but may instead be contingent upon things such as a person's organizational skills, communication skills and ability to be assertive. Individuals with spinal cord injuries who have extremely limited physical function, but who are clear about the outcomes they wish to achieve and can effectively communicate how they wish them to be achieved, may, in fact, have a strong sense of self-efficacy. The present study suggested that the rehabilitation system did not attempt to encourage a sense of self-efficacy in people whose physical function was severely limited. Two participants in this research had high level injuries. One who had only a flicker of movement in one arm commented that he had to "fight all the way" to get into rehabilitation. Once admitted on a probationary basis, he fought against having to use a "sip and puff" chair which, as the name suggests, is operated by sipping and puffing on an apparatus positioned in front of the face. In his words, it took "a bit of convincing" to have the occupational therapist devise a device that enabled him to use his arm movement to operate a regular motorized
chair. The other participant had no movement below her neck, and in her experience the rehabilitation program provided what professionals thought "should be useful," not what "will be useful." With the emphasis on physicality, she found that rehabilitation was not "fitting her for her new life" or teaching her that it was possible to live with some measure of self-respect. These two individuals represent others with high level injuries who, like them, have gone on after rehabilitation to independent community living. It would seem, therefore, that a valuable component of a rehabilitation program would be teaching those who will need assistance to live independently how to communicate their needs and preferences effectively to future providers of practical support, and how to manage relationships with people who provide assistance. As stated earlier, this important area may be beginning to receive some attention. Several authors (Carpenter, 1994; Kerr, & Meyerson, 1987; Marshall, 1984; Whalley-Hammell, 1992) challenge the notion that successful rehabilitation depends on the injured individual's ability to relearn physical skills. As Whalley-Hammell (1992) states,

> The question which may be posed is whether physical skills alone determine successful reintegration into the community and to adjustment to life in an altered form. Satisfying relationships and a meaningful interaction with the social and physical environment depend upon much more than the ability to transfer and dress independently. (p. 318)

**Health**

Health is the last factor affecting transitions that will be discussed. It is important to include mention of this due to the fact
that health, if not attended to carefully, may lead to prolonged and depressing set-backs in the transition of spinal cord injury, as was evidenced in this study. There appears to be very little wellness education included in the rehabilitation program, and individuals with spinal cord injuries often have the unfortunate experience of learning how to take care of their health from their experiences of ill-health. A further difficulty lies in the fact that people with spinal cord injuries often find that family physicians are not well informed about health concerns that affect them. This was experienced by half of the participants in this study and was also evidenced in Carpenter's (1991) research. Perhaps part of becoming familiar with the limits of one's body is learning from experience how its resilience and healing power have been affected as a result of injury. As a person gets to know the limits, he or she also gets to know the warning signs of a potential problem, as well as how to remedy it. It would seem that a stronger emphasis on avoiding health problems and maintaining a healthy lifestyle that includes attention to nutrition and exercise is warranted as people go through the "health" system. The medical model perhaps focuses too narrowly on the immediate health concerns brought about by injury. Once these are stabilized, health is no longer considered a priority issue. As people go on with their lives in their communities, problems that are entirely avoidable can drastically interfere with life, and if allowed to become serious enough, can threaten life. As this study demonstrated, health problems were often cited as the main obstacle that had the potential to prevent a person from progressing, and many others have recognized the importance of attention to health (Bach, 1993, Carpenter, 1991, Oliver, et al., 1988, Steichele, 1995,
Trieschmann, 1992). It seems therefore, that the provision of health and wellness education by the health system is an area worthy of ongoing priority status.

**The Transition Process**

The process of transition is often explained in terms of movement through a certain number of stages. Stage models of the process need to be scrutinized carefully, and approached with great caution. While they help give coherence to a process that can be extraordinarily complex, their structure must be able to accommodate the individualistic nature of human experience. Models that have highly specific stages that are defined in terms of specified behaviors may lead to misinterpretation and misunderstanding when an individual's experience does not correspond with the stages. As has been pointed out, transition is understood in terms of how it is perceived by the individual who is going through it, and as such, no two transitions are alike. A model that cannot accommodate every individual's experience is not appropriate for use in exploring a transition. Models of transition must ensure that the individual's experience remains paramount and is not subverted in service of the stages. In using stage models of transition, the danger exists that they are simply stage models of adjustment under a different name. As discussed in Chapter 2, stage models of adjustment to spinal cord injury have been critiqued for having no empirical basis.

The problem with some models which purport to provide a framework of the process of transition, is that what they actually attempt to provide is a description of the experience of a transition. This is not possible, however, because every experience of transition is
unique. This is perhaps best clarified by example. Schlossberg (1995) cites a "seven stage transition process model" (p. 37) developed by Brammer and Abrego. I would argue, however, that the stages of immobilization, denial or minimization, self-doubt, letting go, testing-out, search for meaning, and integration are an attempt to describe the experience of transition, albeit in general terms. Bridges' (1981) and Schlossberg (1995) have developed models of transition that consist of three stages which do provide a framework for exploring the process of transition. Schlossberg's (1995) stages of moving in, moving through, and moving out of transition describe a process in which an individual's unique experience may be situated. Bridges' (1981) model consisting of endings, a neutral zone, and new beginnings does the same. Both these models are sufficiently broad and flexible to accommodate the diversity of human experience, and as such are suitable for exploring transition. Care must be taken to avoid using the framework of a transition model as the sole, or even the primary, means of assessing a transition. It may be helpful in identifying difficulty at a particular point of transition, but it contributes little to the understanding of the difficulty. Schlossberg (1995) suggests assessment of transition is best accomplished by weighing the positive and negative aspects of four areas; namely, situation, self, support and strategies. Interestingly this corresponds closely to the four main areas identified in this thesis. As described in Chapter 4, Phases of the Experience focused on the situation participants found themselves in at various times during their experiences, and Navigating the Experience identified a key strategy participants adopted that was helpful to them.
in moving forward. The other two areas were Self-Identity and Support.

While the models developed by Bridges (1981) and Schlossberg (1995) provide frameworks that can accommodate the idiosyncratic nature of the transition of spinal cord injury, due to the complexity of this transition, certain characteristics of them deserve additional consideration.

Endings

Bridges (1981) argues convincingly that one of the rules of transition is that "every transition begins with an ending" (p. 11) and that "we have to let go of the old...before we can pick up the new" (p. 11). Endings involve letting go of "the old situation and...the old identity that went with it" (Bridges, 1986, p. 25). It must be remembered that spinal cord injury is a massive transition that likely involves at least one secondary major transition. Writings and discussions about transitions usually relate to only one major transition, with some of the more typical examples referred to being marriage, divorce, and retirement. The magnitude and number of endings involved in the transition of spinal cord injury must be considered. There may be endings related to relationships, career and employment, leisure activity, location of residence, and there are likely to be endings in terms of the roles that contribute to a person's sense of self. According to Bridges' conceptualization of the transition process, coming to terms with endings is a prerequisite for moving on toward a new beginning, and endings are presented as "all or nothing". He proposes that "endings must be dealt with if we are to move on to whatever comes next in our lives. The new growth cannot take root on
ground still covered with the old, and endings are the clearing process" (p. 91).

The task of dealing with endings is highly complex for people with spinal cord injuries, not just because of the number and magnitude of them, but, as this research has shown, exactly what has ended as a result of injury is not immediately known. Unlike a planned retirement when a person knows he or she will no longer work after the date on which the transition event takes place, as discussed earlier in this chapter, people with spinal cord injuries do not know what their capabilities will be after injury in terms of physical and social activity, and the roles they will be able to enact. The process of sorting out endings can be lengthy as people discover alternative ways of carrying out activities, and find ways to enact roles they previously associated with different behaviors. In fact, it may be advantageous for people with spinal cord injuries not to come to terms with endings too soon. As this study showed, declarations from others that one's ability to carry out a certain activity had ended served as an impetus to find a way to do it. Not accepting endings too readily may encourage growth, whereas clearing out old activities and roles prematurely may prevent growth. Again we are reminded of Dan, who ten years after his injury was not able to envision himself in the role of partner, but at the same time he was not convinced that this role represented a permanent ending in his life. He was willing to leave the door open to future growth.

While it may not be helpful to come to terms with endings too soon, it is also not helpful to cling to undeniable endings. This is often associated with false hope, or unrealistic hope, as Hickey (1986) calls it.
She contends, however, that unrealistic hope may "serve a useful purpose for a period of time [in that] it may provide...necessary time for assimilating reserves and coping skills so that [one] can deal realistically with [his or her]...experience" (p. 135). This study showed that one of the meanings of acceptance for people with spinal cord injuries was being fully cognizant of the situation they found themselves in. This involves recognition of what one is no longer able to do. It was evident that people recognized the necessity of accepting undeniable endings in order to move forward, but this too, can take time. As one participant said, "You're battling inside yourself for two to three years until you decide there's too much energy going for this. Let's just accept it and get on with life."

It was evident in the disorientation stage that often people experienced the sense that injury had caused the life they had been leading to end, and that they were in a position of having to "start life over again." As they began again "from scratch", new beginnings first took place in rehabilitation and were related mainly to learning physical tasks. It is interesting to note that when individuals had returned to their communities, after the coasting phase of the experience, which for many culminated with the critical turning point, new beginnings began to be more related to the pursuit of life goals. It seems a change in perspective takes place after the critical turning point and new beginnings are much more life oriented than task oriented. This is when "life started" for one participant, and when another "got back into life." While the process of discovering new beginnings is ongoing, it does seem this important shift in perspective
signifies the point at which individuals once again felt engaged in the enterprise of living.

Contrary to what Bridges (1981) suggests, this study showed that it was possible to move forward in spite of unresolved endings. In instances when the loss involved was extremely difficult to come to terms with, including recognition of the difficulty and being fully cognizant of it as a part of the situation seemed to encourage people to find a way of dealing with it that minimized its interference in their ability to move ahead. It was clear that over time many new beginnings were made as endings were sorted out. It may be more appropriate to think of endings and beginnings as a process of discovery, rather than a task of clearing away the old to make room for the new in the transition of spinal cord injury.

The Neutral Zone

The neutral zone in Bridges' model is "an interim period between one orientation that is no longer appropriate and another that does not yet exist" (Bridges, 1986, p. 29). He describes this as a no-man's-land in time when everything feels unreal.

It is a time of loss and confusion, a time when hope alternates with despair and new ideas alternate with a sense of meaninglessness, a time when the best one can do sometimes is go through the motions. But it is also the time when the real reorientation that is at the heart of transition is taking place. (Bridges, 1986, p. 25)

The neutral zone is presented as the interval between endings and new beginnings, and according to Bridges (1981) it is characterized by the tendency for people to spend time alone and not to do much of anything. During this "apparently unproductive time-out" (p. 114), he
proposes that important inner business is being conducted. Although Bridges speaks of the neutral zone mainly as a mid-period of transition, it seems the qualities of it are most significant, not when it occurs. He points out, for instance, that it may precede a visible ending when an inner ending has taken place, such as when a person is still going to work but is no longer engaged in what they are doing because a decision has been made to leave the job. Identifying a middle span of time bordered by an ending and a new beginning may be realistic when dealing with one major transition. It is not possible, or desirable, to do this with the transition of spinal cord injury. As stated, multiple transitions are involved and many endings and new beginnings occur over a protracted period of time. To conceive of the time during which these take place as a neutral middle section of a three part transition process would clearly be erroneous. As has been shown in this study, intense, active learning takes place in the discovery of endings and new beginnings.

The coasting phase of the experience of living with spinal cord injury appears to be characterized by qualities resembling those of the neutral zone. During this phase people were often isolated and engaged in limited, and unproductive, activity. As discussed earlier in relation to the uncertainty of the duration of the transition of spinal cord injury, a period of coasting may occur in response to overwhelming uncertainty about one's capabilities once they are faced with interacting in the 'real' world after rehabilitation. Cogswell (1984) notes that upon returning to the community individuals find that "one world is lost and another is yet to be gained" (p. 159). She found that this was a time of self-imposed moratorium characterized by
emptiness. It may be that a neutral zone between the demands and the strain of rehabilitation, and venturing out into the social world of the community is necessary. This period of coasting may be a time for the experience thus far to be assimilated and for people to fortify their energy reserves so they may begin to take the risks that will allow them to move ahead and "get back into life." Yoshida (1991) found that upon return to the community people spent "variable amounts of time in 'isolation' to better learn about themselves or 'to integrate the disabled and non-disabled selves'" (p. 88-89). Similarly, Carpenter (1991) describes a time which is particularly salient during the first two years post-injury when preinjury conceptions of self do not apply and new ones have not yet emerged during rehabilitation or on initially returning to the community. She found people experienced a "sense of being arrested in time" (p. 91) during this period. Cogswell (1984) also found that individuals were unclear about their identities when they returned to the community. The current study found that roles may begin to be sorted out upon return to the community when a person can learn through experience which have ended and which have not. Thus, self-identity may be confused during the neutral time of coasting which adds to the complexity of this period in the transition of spinal cord injury.

This discussion of the neutral zone underscores the importance of using a transition framework as a reference tool in exploring the transition of spinal cord injury. It is not appropriate to dissect the experience of living with spinal cord injury into three distinct parts in an attempt to fit the experience into a transition framework. It must be emphasized that the specific parts of a transition framework are
best defined by their characteristics, rather than a presumed order of occurrence. Directing too much attention to their position may lead to misuse of the framework and misinterpretation of the experience.

**Moving In, Moving Through and Moving Out of Transition**

Schlossberg (1995) presents a very general description of her model of moving in, moving through and moving out of transition. This is perhaps indicative of her belief that understanding transition is achieved through examining how the individual experiencing it perceives its impact. Judging by the lack of detail in her explanation of the stages, it seems that understanding the process of transition is of secondary, if not minor, importance. Schlossberg’s model emphasizes the fluid nature of the process and offers a highly flexible framework that can accommodate the multiple endings and new beginnings inherent in the transition of spinal cord injury. Moving out of transition involves endings, moving in involves becoming familiar with new roles, relationships, routines and assumptions, and moving through includes a period of emptiness and confusion, and individuals "grope for new roles, relationships, routines [and] assumptions" (p. 44).

Schlossberg (1995) points out that either moving in or moving out can signify the beginning of transition, but once a person has moved in, the task is to become familiar with "the rules, regulations, norms, and expectations of the new system" (p. 44). This brings attention to a characteristic of the transition of spinal cord injury that contributes to its complexity. Going through the transition involves becoming familiar with two separate systems, each of which have different rules, regulations, norms and expectations. The first of these is the rehabilitation system, and the second is the 'real world' system.
Schlossberg's stage of moving through transition is presented very briefly, but she suggests that it begins once a person "knows the ropes" (p. 45) of the new situation. Using the concepts of her framework to explore the transition of spinal cord injury, it would seem that as people learn the ropes in the rehabilitation system they also begin to move through their new situation and move out of the old one as they discover endings and new beginnings. However, as has been pointed out, the discovery of endings and beginnings is limited by the rehabilitation setting and thus, only so much movement out of the old situation can occur. Upon return to the community, the process of discovery can resume as people begin to experience the reality of living in the world as a person who has a disability. It seems that it is through this 'real life' experience that people can come to truly understand the impact spinal cord injury has had on their situation and on their roles and relationships. Thus, movement resumes along with another process of discovery related more to the social self, as people "learn the ropes" of living in the social world of the community. It seems as though a false start in the transition process is created by the gap between rehabilitation and the community which only adds to the difficulty of going through the transition. Although it is impossible to close this gap completely, simply because the rehabilitation environment is different from one's home environment, it is possible for it to be narrowed considerably, and for more continuity to be brought to the transition process. It would appear that developing ways to achieve this is an important area worthy of future investigation. The appeal of Schlossberg's model is that it is flexible enough that the stages can overlap considerably and can accommodate
the gradual process of discovering and letting go of endings and the
discovery and pursuit of new beginnings, as people move through the
experience living with a spinal cord injury.

**Conclusion**

Although this study presents the commonality of ten people's experiences, it is recognized that each person's experience of living with spinal cord injury is unique, and is shaped by aspects of self and the physical and social environments. The growing call for the health care community to develop an individualized approach to spinal cord injury (Carpenter, 1991, Cogswell, 1984, Quigley, 1995, Richards, & Metcalf, 1986, Steichele, 1995) is evidence of increasing recognition that the experience of living with an injury is idiosyncratic and is best understood from the perspective of the individual. Perhaps the most powerful insight to emerge from this research is that injury to the spinal cord is a transition event, and the experience of living with spinal cord injury involves a transition process. As explained earlier, understanding the perspective of the individual is paramount according to transition theory.

Transition theory offers an excellent alternative to the medical model for exploring and understanding the complex experience of living with a spinal cord injury. Applying it to the investigation of the experience offers the possibility of correcting the deficiencies inherent in the traditional approach to spinal cord injury that are outlined in Chapter 2. Transition theory draws attention away from the condition of being spinal cord injured and focuses on the way the event of spinal cord injury impacts all aspects of a person's life. Understanding of the transition comes about from concurrent analysis of the individual's
perspective of self and environment over the long term. Investigation of the experience of spinal cord injury as a transition, therefore, demands attention to the individual's perspective, the inclusion of context, and longitudinal study, all of which are lacking in the traditional approach. These are limitations that have historically prohibited access to the experience. Transition theory calls for the removal of these limitations, and provides broad access to the experience of living with spinal cord injury.

**Implications for Research and Practice**

The experience of living with spinal cord injury begins at the moment of injury and continues for the remainder of an individual's life. In order to bring forth understanding about that experience and achieve the objective of this study, this research was designed to accommodate the full latitude of each participant's experience. The insights that have emerged from the focus on the continuity of the experience, and from the broad scope of the study, have important implications for both research and practice.

This study has suggested that the process of adjustment and the process of transition may be one and the same. The conceptualization of adjustment as the course of an person's response to change is very different from the health care community's perception of it as an externally defined state. For injured individuals, it appears that adjustment may be the same thing as going through the experience of living with spinal cord injury. The individual is the evaluator of the level of satisfaction at any given time during the experience, and is ultimately the only one who can alter it. For health care professionals, it seems that adjustment is a state that is defined according to their
personal beliefs and values. This is apparent by the way research is typically conducted, and as has been pointed out, researchers are often members of the health care community. Without knowledge of the individual's life experience, they are the evaluators of either success or failure in terms of adjustment. The great disparity between these views of adjustment implies that efforts to "help a person adjust" may be misdirected.

Various health professionals have specific involvement with people with spinal cord injuries, and offer support by offering the benefit of their knowledge. Physiotherapists, occupational therapists, equipment technicians, and so on, all require a particular degree of familiarity with a person's experience in order for their support to be most helpful. Psychosocial issues can affect an individual's receptivity to the support that is offered, and while it is not reasonable to expect professionals to be involved outside their area of expertise, it would seem that it would be advantageous to create an environment in which the impact of spinal cord injury on the social realm is appreciated. This research suggested that provision of specific professional support for psychosocial concerns may be problematic in that it may not be well received. More investigation is needed to clarify if this is the case, and, if so, to determine what factors are involved. It may be that lack of understanding of the experience is one of them.

This study brought forth some new ideas about adjustment and defined it according to the characteristics that it was found to possess. Much more work needs to be done towards deriving an empirically valid definition of adjustment. This is important, considering that health care programs in hospitals, rehabilitation facilities, and
communities may be based on perceptions of adjustment that do not coincide with those held by the people receiving the service.

While transition theory was introduced as a possible alternative to the traditional medical perspective of spinal cord injury, it was beyond the scope of this study to suggest future service delivery models based on a transition perspective. It would seem that this is a rich area for future investigation that could lead to significant changes in ideology and practice. It would also seem that a critical prelude to developing new programs and practices would be to assess the view of spinal cord injury generally held by researchers and practitioners. Research related to this may indicate the climate for change, and determine the needs for further knowledge and education. It is especially important for professionals who are interested in pursuing the alternative offered by transition theory to examine how their beliefs, assumptions and values inform their outlook on spinal cord injury. Transition theory offers the opportunity for collaboration between people with spinal cord injuries and health professionals that can help close the gap created by social isolation. Both parties must be willing to enter into dialogue and must be interested in bringing forth understanding of the injured individual's perspective of living with spinal cord injury.

The lack of continuity between rehabilitation and community living has been well documented (Carpenter, 1991, Cogswell, 1984, Dew, et al., 1983, Oliver, et al., 1988, Steichele, 1995, Vargo, 1982), and evidence is conclusive that this is a difficulty that needs to be addressed. The current study corroborates the need for further research focused on identifying and implementing changes in practice
that will help correct this problem. More importantly, however, it provides further understanding of the transition of leaving rehabilitation and entering the community. This research suggested that individuals are not truly able to sort out confusion they have surrounding their social roles until they are back in the social environment of the 'real' world. Other studies (Carpenter, 1991, Cogswell, 1984, Yoshida, 1991) have established that people do struggle with issues of self-identity upon return to the community. Future research aimed at in-depth examination of the impact spinal cord injury has on roles may bring forth useful knowledge on how to better prepare individuals for their return to their home environments. Additional research may elucidate which roles are most affected, the reasons why, and how the disruption was resolved. This may help in the development and implementation of programs that begin in rehabilitation and carry over into the community which are designed to reduce the stress associated with role disruption.

The present study suggested one's role as an adult becomes disrupted as a result of injury, and that the disruption is exacerbated by the rehabilitation environment. More research is needed to confirm the impact of the rehabilitation experience on roles. It would seem that this would provide crucial information for consideration in developing programs intended to minimize the impact of spinal cord injury on roles.

This thesis showed that self-efficacy was impacted by spinal cord injury, and that doubts about capabilities also contributed to the stress of returning to the community. It was suggested that self-efficacy in relation to physical capability may be fostered in rehabilitation, but
that one's sense of self-efficacy in the social realm may not come about until one is confronted with the 'real' social world. Additional research exploring this area would be valuable in bringing about more detailed understanding of how self-efficacy is affected throughout the experience of living with spinal cord injury, and again, in understanding how the rehabilitation experience affects one's overall sense of self-efficacy. The information such research reveals would be useful in determining how to reduce the stress associated with doubts about self-efficacy when individuals return to the community.

Coasting and the critical turning point were identified in this study as two of the phases of living with spinal cord injury. Coasting is a phenomenon that has just been touched on by research, and evidence suggesting a critical turning point has been documented only once. The results of the current research suggest coasting is often followed by a critical turning point. Both phases need to be substantiated by further research, and their possible link to the stress of returning to the community needs further investigation. This study suggested that coasting may be a response to overwhelming uncertainty about one's capabilities and roles. The period of coasting may continue for years, and further exploration may demonstrate how the health care system can best support a person so that this phase does not become an unduly prolonged and negative part of the experience of living with spinal cord injury.

As pointed out earlier in Chapter 4, the critical turning point was a very significant aspect of the experience. It represents a time when individual's were faced with the choice of embracing hope or surrendering to despair. If for no other reason, it needs to be
corroborated and understood because the choice may, in fact, be between life and death. As well, a decision to pursue life at this point signified a strong sense of optimism and responsibility that allowed individuals to forge ahead in the pursuit of life goals. Further investigation of the dynamics of the critical turning point may also bring insights about the function of support and hope, since both have important influences during this phase. Support and hope both play highly influential, key roles throughout the experience of living with spinal cord injury, and because they are such crucial elements, research pertaining to their dynamics and function in the changing experience may contribute valuable knowledge about how and when they can be most beneficial.

Exploring the experience of living with spinal cord injury as a transition has brought attention to many possible avenues for future research which may ultimately bring about changes in practice. While the suggested areas of research pertain to individual aspects of the experience, they have been situated and explored within the context of the experience from which they emerged. Thus, they are not separate from it, as are many of the isolated aspects that have previously been studied. The results of this study, and the interpretation of them in relation to transition theory, have provided a comprehensive examination of the experience of living with spinal cord injury. Perhaps the greatest implication of this research is that in viewing spinal cord injury as a transition, the perspectives of professionals and persons who have injuries can be brought into closer alignment, and the response of the medical community to the event of spinal cord injury can be informed by greater understanding of the life experience.
that follows. Above all, this study suggests that valuing the perspectives and input of people with spinal cord injuries, and upholding an ideology that sees all people as interdependent participants and contributors in society, are two of the most important factors in research and other efforts to bring about change in practice.

Chapter Summary

This chapter provided a rationale for using transition theory to explore the experience of living with spinal cord injury. Transition theory was explained and spinal cord injury was identified as a specific type of transition. The impact of the transition on routines, assumptions, roles, and relationships was discussed. This was followed by a discussion of factors affecting transition that are particularly relevant to spinal cord injury. Included in this was lengthy examination of roles, duration of transition, and support. The use of models of transition was examined, and the need to use such models judiciously was pointed out. The transition of spinal cord injury was considered in relation to models developed by Bridges' (1981) and Schlossberg (1995). Several unique characteristics of the transition which must be appreciated when considering these process models were identified, including the multiple transitions and endings involved in spinal cord injury. The chapter closed by outlining the implications for research and practice that are suggested by this research.
REFERENCES


APPENDIX A

LETTER OF INTRODUCTION TO BCPA MEMBERS
August 2, 1995

Dear BCPA Member:

I have asked the B.C. Paraplegic Association to forward this letter to members who may be interested in participating in a study I am conducting as a requirement for my Master's degree. I am currently completing my second year of the Counselling Psychology program at the University of B.C.

The purpose of my study is to explore the experience of living with spinal cord injury, from the point of view of the injured individual. Specifically, events which are perceived to have had a significant positive or negative effect on the experience will be examined, as will the notion of adjustment and what it means to the person with a spinal cord injury.

Participating in the study will take approximately 2 to 2 1/2 hours of your time, and will involve:

- An unstructured interview lasting approximately 1 1/2 to 2 hours during which you will be asked to recount your experience of living with a spinal cord injury from time of injury to the present. You will be asked to identify and describe significant positive and negative events that have affected your experience. You will also be asked to identify future goals and what is necessary in order that they may be achieved. These events and goals will be plotted on a Life Line. This is a simple way of visually illustrating key points in your life. These points are plotted according to the age at which they occurred and either their positive or negative intensity, on a scale of one to ten, with ten being the most intense. To conclude the interview, you will be asked what adjustment means to you, as it relates to your experience of living with a spinal cord injury.

This interview will be audio-taped and transcribed by a hired typist. Tapes, transcripts and the Life Line will be number coded to ensure confidentiality is maintained. Once the study is completed, tapes will be erased and the interview transcript, the Life Line and the background information will be shredded.
APPENDIX B

LETTER OF INTRODUCTION TO MUTUAL CONTACTS
Dear

Your name was referred to me by a mutual contact as a possible participant in a study I am conducting as a requirement for my Master's degree. I am currently completing my second year of the Counselling Psychology program at the University of B.C.

The purpose of my study is to explore the experience of living with a spinal cord injury, from the point of view of the injured individual. Specifically, events which are perceived to have had a significant positive or negative effect on the experience will be examined, as will the notion of adjustment and what it means to the person with a spinal cord injury.

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.../2
APPENDIX C

PARTICIPANT CONSENT FORM
• A final meeting lasting approximately one-half hour to review the researcher's summary of the interview. At this time you may add further information and you will be asked to point out any inaccuracies in the summary.

It is important to note that consenting to participate does not obligate you to remain in the study if, for any reason you wish to withdraw. You may withdraw at any time without question, and with absolutely no consequence.

I, ____________________________, acknowledge that I have read and understand this consent form. I have received a copy of it for my records.

_________________________              _______________________
SIGNATURE                  DATE

I, ____________________________, consent to participate in this study as it has been described.

_________________________              _______________________
SIGNATURE                  DATE
APPENDIX D

PARTICIPANT INFORMATION FORM
# Participant Information

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APPENDIX E

THE LIFE LINE
APPENDIX F

DESCRIPTIONS OF CATEGORIES OF EXPERIENCE USED FOR PEER REVIEW
PHASES OF THE EXPERIENCE

DISORIENTATION

Statements that indicate participants'

- sense of confusion, and/or

- lack of understanding about their injury and its consequences, and/or

- sense of an uncertain and unstable future.

REHABILITATION

General reflections about how participants experienced rehabilitation (as opposed to descriptions of particular experiences that took place in the rehabilitation setting).

ENTERING THE COMMUNITY

Statements in which participants speak about community living in comparison to life in the rehabilitation setting.

Statements that describe participants' experiences of entrance into the community.

COASTING

Statements in which participants make reference to a period of limited activity, or describe such a period.

THE CRITICAL TURNING POINT

Not included in peer review due to the difficulty of identification without knowledge of the participant's full experience.
NAVIGATING THE EXPERIENCE

FINDING AFFILIATION

Statements that indicate

• participants feel an affiliation with other people with disabilities
• participants see possibility when they see themselves in relation to other people with disabilities
• participants learn from others' input/experience (physical tasks, a different attitude or point of view)

PURSUING POSSIBILITY

Statements that describe a strategy of seeking alternatives.

Statements that describe a situation in which participants engaged in problem solving (sought alternatives).

Statements which indicate participants' openness to possibility.
SELF-IDENTITY

DESTABILIZATION OF IDENTITY

Statements which indicate participants experience themselves as physically changed (often occurs when one has difficulty carrying out tasks or is completely unable to do so).

Descriptions of social situations in which a difference between participant and others is perceived (includes being stared at).

CONNECTION TO SELF

A group of statements in which:

- an aspect of participant's personality pre-injury is identified, AND manifestations of it post-injury are described.

Statements which indicate participants believe that ultimately personality does not change as a result of injury.

Statements which indicate participants continue to identify with an aspect of their personality post-injury.

CONNECTION TO COMPETENT SELF

Statements in which participants

- speak about accomplishment in general terms, or
- describe a particular accomplishment (achieving a goal).

Statements in which participants describe themselves as productive and/or competitive.
AFFIRMATION OF SELF

Statements indicating participants consider their disability to be of little or no consequence to their self-identity.

Statements indicating that participants consider the self ("who they are as a person") to be primary in terms of self-identity, and disability to be secondary.

REFLECTION OF SELF FROM OTHERS

Descriptions of social interactions/relationships/situations in which participant perceives others

- see beyond their disability to who he/she is or,
- are not able to see beyond the disability
SUPPORT

THE NATURE OF SUPPORT

Statements that describe the ways in which participants were supported (motivation, encouragement, emotional availability, active participation). May also include identification of who is providing support.

THE PROVIDERS OF SUPPORT

Statements which identify who provided support to participants. The ways in which participants were supported is NOT described.