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THE EXPERIENCE OF SPINAL CORD INJURY AS TRANSFORMATIVE
LEARNING

by

CHRISTINE CARPENTER

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Department of Administrative, Adult and Higher Education

The University of British Columbia
Vancouver, Canada

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ABSTRACT

The purpose of this study is to explore individual conceptions of the experience of traumatic spinal cord injury from the perspective of adult learning. A qualitative research approach was chosen as the most appropriate to explore these meanings. The methodology for this study was both descriptive and interpretive. Data collection took the form of semi-structured in-depth interviews. The research was essentially exploratory. Commonalities of meaning attributed to the injury were revealed through analysis of the data and grouped into three thematic categories; rediscovery of self, redefining disability and establishing a new identity.

These themes, whilst representing commonalities, revealed the complex and multidimensional nature of each individual's experience. The disability and overall sense of loss were initially symbolized by the physical changes or the external experience of disability. These are separate from the internal concept of 'self' which was perceived by the individuals as being the same as pre-injury. The findings suggest that an inner conflict between the external or public 'self' and the internal or private 'self' develops which can best be described as an experiential split.

The theme of rediscovering self is concerned with those components of the post-injury experience which inhibit or facilitate a reintegration of the internal and external selves. The inhibiting factors identified included the loss of control over physical functioning and capabilities, alienation from the 'real world,' the restrictive environment and instructional limitations of the rehabilitation facility and the attitudes of health professionals. The process was found to be facilitated

by the continuity of their sense of self, a gradual build-up of a new framework of experience and personal resources accrued from their pre-injury history and social context.

The theme of redefining disability was achieved by challenging the attitudes and stereotypes espoused by health professionals and society, and an assimilation of a new sense of coherence. The latter was seen as occurring through attributing meaning to the cause of the injury, expanding the range of available options and developing new value priorities.

The third theme of the establishment of a new identity was found to be associated with making comparisons with others by which self-esteem can be enhanced, by association and dialogue with a peer minority, by creating intimacy with significant others and new ways of interacting with society.

These themes bear little relationship to the instructional content of current rehabilitation programs, and defy explanation through the traditional learning perspective of skill acquisition and behavioral change which has dominated rehabilitation practice, and to which research is primarily directed. The data yielded a way of understanding the experience of spinal cord injury which is not adequately expressed in the literature. It became apparent that these individuals were engaged upon a complex learning process.

A theory of transformative learning proposed by Mezirow was introduced as a possible alternative, or adjunct to, the educational model of rehabilitation service provision. Central to this theory are two dimensions of meaning described as meaning schemes and meaning perspectives and the unique adult characteristic of critical reflection.

The subjects in this study recognized the learning involved in questioning old meaning perspectives and creating new ones. By reflecting and acting on these new meaning perspectives the facts and implications of disability became integrated into a chosen lifestyle.

Implications for rehabilitation practice are that the target of an educational intervention may not, in fact, be the clients but the health professionals involved in providing instruction and care. A greater understanding of the experience of traumatic spinal cord injury over time, and the uniquely individual learning process involved, would facilitate a more client centred and relevant approach to instruction.

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Chapter One: INTRODUCTION

The general focus of this thesis is how persons with traumatic spinal cord injury experience the injury and its consequences within the first five years post injury, and the meanings attached to this particular life event by which these individuals make sense of what is happening. As the research study unfolded it became apparent that these individuals were engaged on a complex and personal adult learning process. This research focus emerged, in part, as a result of my involvement with a Fertility Clinic established at a major rehabilitation centre. The Clinic provided a unique opportunity for me to meet and learn from individuals who had been injured between 3 and 20 years ago. In the course of conducting interviews it became apparent to me that the clients all considered themselves 'successfully' rehabilitated. The rehabilitation setting, to which they rarely if ever returned after discharge, represented merely a phase in a greatly extended and complex learning process. It became obvious that these individuals had gained an understanding of their rehabilitation, although exactly what it entailed, and how it had been achieved remained unclear.

If indeed 'successful' rehabilitation, as defined by the individuals themselves, is achieved through a learning process which involves making meaning of the experience of severe injury, then research which facilitates access to the learner's perspective would provide valuable information upon which to review and direct rehabilitation practice. Rehabilitation practice is increasingly being based on an educational or health model of service provision, and the need to expand this model beyond the traditional focus on behaviors to incorporate personal and

contextual factors is recognised. The purpose of this study is to explore individual conceptions of "rehabilitation" of disability resulting from spinal cord injury from the perspective of adult learning.

Spinal Cord Injury

Traumatic spinal cord injury causes profound and devastating effects on all functions of the body. The physiological and medical implications of these physical changes have been well documented. In 1927 the neurosurgeon Dr. Harvey Cushing (cited in Maddox, 1987) summarized the culmination of centuries of thought on the prognosis of spinal cord injury when he wrote that only spinal injured people with partial damage to the spinal cord lived. The subject of rehabilitation was seldom broached prior to World War II. Dr. John Young (cited in Maddox, 1987) noted that "...any attempt to restore such persons to their former activities seemed out of the question and the view generally held was the sooner he died the better for all concerned" (p. 25). Into the 1940s, despite the advent of neurosurgery, treatment and survival of cord-injured people remained problematic if not nightmarish.

In response to the injuries to both military personnel and civilians resulting from World War II, Great Britain initiated a fundamentally new approach to the management of spinal cord injury. By centralizing treatment in Spinal Injury Units, the most famous being Stoke Mandeville Hospital directed by Sir Ludwig Guttman, it was hoped that systematic study of the treatment of people paralyzed as a result of spinal cord injury would be facilitated. Guttman (1973) sought to:

Rescue these men and women from the human scrap heap and to return most of them, inspite of profound disability, to the community as useful and respected citizens.

The chief object was not just to preserve life but to give them a purpose in life ... naturally, the practical application of this philosophy was no simple task, considering the thousands of years prejudice towards spinal cord injury sufferers.(p. 9)

It is this tradition, established as recently as the last half of this century, which forms the context of rehabilitation treatment programs which were finally institutionalized in the United States and Canada in the 1970s.

Injury statistics, related to age, gender, cause of injury, and number of injuries per capita in British Columbia are currently similar to those in the United States where data collection methods have been more standardized. In the States there are approximately 8000 new injuries per year. In British Columbia there are approximately 130 new cases a year. The number of new cases in Canada per year is not accurately known and varies considerable between the provinces. Spinal cord injury happens mostly to men (82 percent)¹ who are below 25 years of age. The most common cause of injury is the motor vehicle accident. More than half of the injuries result in quadriplegia (53 percent), however the number of incomplete injuries has increased dramatically over the past 10 years, explained in part by improved roadside management.

The severity of the injury is related to the level of the spinal cord involved and the degree of damage sustained. The spinal cord is made up of thousands of nerve fibres linking the brain with the various parts

¹ Therefore, all references to gender use the appropriate male pronoun.

of the body. It is enclosed within the vertebrae which make up the vertebral column. This vertebral column is divided into four sections of vertebrae: cervical (neck), thoracic (trunk) and lumbar and sacral (the lower back). If the spinal cord is damaged in any of these sections vital communication between the brain and the rest of the body is broken, and messages about feeling and movement cannot be conveyed. The level of injury to the spinal cord is referred to by the level of vertebra at which it occurs, thus 'C5' means injury at the level of the fifth cervical vertebra. Quadriplegia means that the damage to the spinal cord was at the cervical level and the upper part of the body, including the arms and hands, as well as the lower part of the body, is paralyzed. Paraplegia arises from damage to the spinal cord at thoracic or lumbar levels, involving paralysis of the lower trunk and legs.

The extent of injury to the spinal cord, and the level at which it occurs, will determine the function still available to the person. The injury may be 'complete' or 'incomplete' meaning that the damage to the spinal cord is total or partial. It is not only simply sensation and movement which is affected by the injury, the functioning of other systems such as the respiratory, circulatory, gastrointestinal, urinary and sexual may be altered. These radical changes of bodily function make the newly injured person prone to a number of serious, and frequently life threatening, medical complications. The most common complications include respiratory insufficiency, bladder infections, bowel difficulties, uncontrolled blood pressure changes, spasticity and skin breakdown. With time the body reasserts a degree of function, and skills and preventive measures can be learnt, which minimize these

potential complications but this requires specialized and extensive treatment.

Since 1975 all spinal cord injuries occurring in British Columbia have been provided emergency treatment at the nearest acute hospital and, when medically stable, transported to the Acute Spinal Cord Injury Unit in Vancouver. During the acute phase the focus of treatment is stabilization of the injury and medical management of the consequences of spinal cord injury. Rehabilitation continues in the rehabilitation centre and incorporates physical restoration (28-180 days after injury), vocational preparation, and community placement. The major disability resulting from spinal cord injury, the prolonged time spent in institutions, and the specialized assistance and equipment required make it one of society's most expensive injuries.

The Framework of Rehabilitation

Rehabilitation programs are designed to teach the person with spinal cord injury to perform the activities required for survival as an independent adult. Some persons with quadriplegia must learn to identify needs, teach and organize others to do the necessary activities for his survival. Traditionally, rehabilitation programs have focused on teaching techniques of mobility and activities of daily living (ADL). Mobility training includes learning to change positions in bed, to use a wheelchair, to transfer between the wheelchair and bed, toilet and vehicle, to drive a vehicle using hand controls, and for persons with paraplegia, ambulation with braces and crutches. ADL includes such activities as bathing, grooming, getting dressed, skin care, bladder and bowel management, eating and homemaking skills. For quadriplegics

with limited hand function, ADL training becomes a primary focus of rehabilitation, frequently requiring the assistance of adaptive devices such as splints. Individuals of many health professional disciplines are involved in the rehabilitation process, including physicians, nurses, physiotherapists, occupational therapists, social workers, vocational counselors, psychologists, recreational therapists, orthotists (experts in brace manufacture), dieticians, and often biomedical engineers.

The practice of rehabilitation medicine has been dominated by the medical-surgical (medical model) approach to acute disability management and biologically oriented research. Rehabilitation programs continue to be designed and implemented by professionals, the input of persons with disabilities being solicited only occasionally with no authority to shape programs or allocate resources. Willems' (1976) description of rehabilitation "as comprising programmatic arrangements designed to restore or substitute for lost or altered function in a person's repertoire, to teach new kinds of performance and new kinds of relations to the environment" (p. 215) exemplifies this orientation. Measures of success in rehabilitation centres focus on physical skills, and discharge from rehabilitation is defined in terms of mastering those tasks. It is the equally profound psychosocial changes inherent in the rehabilitation process, by which a person learns to live and compete in a world designed for, and dominated by, able bodied persons which need to be identified and explored.

It is becoming obvious that the content of the traditional rehabilitation program, focusing as it has on ADL and mobility, is inadequate to meet the needs of individuals experiencing spinal cord injury and who have the imperative of living in a complex and

competitive environment. Nor is this type of program addressing the problems of aging with a disability. The benefit from rehabilitation to be sought by the client is limited by formalized facility programs and the service delivery orientation of health professionals involved.

Increasingly these limitations are being recognised and an expanded view of rehabilitation, as a learning experience which is a dynamic process that starts at the moment of injury and continues for the remainder of the person's life (Trieschmann, 1988) is being developed. In reframing the definition of rehabilitation it can be seen as a learning process in which professionals on the rehabilitation team are seen as teachers or resource persons. Defined in this way rehabilitation does not end at the moment of discharge from the rehabilitation centre, but rather begins when the person practices the techniques introduced in the centre, and applies them to coping with the real world. This view of rehabilitation has been further complemented in recent years by the identification of the educational or health model of delivery of medical services (Anderson, 1978, Wright 1983, Bartlett & Windsor, 1985, Lorig & Laurin, 1985 and Trieschmann, 1988). The educational model is characterized by a systems rather than a fragmented approach; problem prevention rather than crisis intervention. The assumptions inherent in this model are that, firstly, health behaviors are, at least in some instances, mediators of health status. Second, health behaviors are the results of knowledge, beliefs, and attitudes. Third, specific behaviors, when changed, improve health (Bartlett and Windsor, 1985). Within the educational frame of reference persons with disability are seen as active participants in planning and implementing their own care. Despite the broad nature of the educational model it does provides a

significant alternative to the traditional medical model of health care delivery. In the former it is assumed that the person is healthy but now must learn a series of behaviors so that return to the world outside of the hospital is facilitated (Trieschmann, 1988).

The development and effective implementation of the educational model requires a redefinition of rehabilitation and health care delivery, and it is this prospect of future change that formed the underlying premise from which I began to plan this research project. My experience as a physiotherapist, specialising for fifteen years in the treatment and management of spinal cord injury, lead to a clear understanding and appreciation of the physical ramifications of the injury, the diversity of persons involved, and the respective coping skills which they bring to bear on this totally new learning experience. It also became clear that the role of physiotherapist in facilitating rehabilitation was primarily that of educator, a role for which an adult education approach appeared to have much to offer in terms of theoretical background and guidelines for practice.

Adult education has been instrumental in shifting the focus from a pedagogic approach to teaching practice to the individual learner as paramount in the learning transaction (Knowles, 1980 & Brookfield, 1986). Knowles' declaration that the perception of being essentially self-directing is a unique characteristic of an adult, and that educational efforts should be directed towards facilitating this latent skill, has had considerable influence on nursing and patient education theory. An educational perspective is essential for this research project, and is also in accordance with other approaches, which stress the centrality of the individual in the rehabilitation process.

The Research Problem

The research problem arose from a broad theme of emerging interest in the personal response to traumatic spinal cord injury, and in the unique and individual ways people learnt to cope over time with the consequences of the injury. Through my involvement with the rehabilitation system in Vancouver, and more recent work at the Fertility Clinic, I developed social and professional relationships with persons who have lived with spinal cord injury for many years. This contact with these "old hands," as they called themselves, caused me to make a careful accounting of my own responses and reactions to spinal cord injury and the manner in which these responses influenced my professional practice. It served to keep me in touch with the phenomenon of people's lives following spinal cord injury. This growing knowledge, whilst undoubtedly enhancing my professional practice, also sensitized me to the 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. In general, spinal cord injury is viewed, by health professionals, as a personal tragedy having devastating and permanent effects on an individual's life. An individual's response to the injury is seen to occur in accordance with theories of stages of psychological adjustment. Rehabilitation programs are directed primarily towards managing issues of survival. My conversations with individuals over the years suggested that their responses to spinal cord injury could be more effectively understood in the light of "significant life event," and as involving a whole range of uniquely personal, social and economic factors, not simply as a function of the extent of physical disability.

It has become clear that the way individuals subjectively experience spinal cord injury is profoundly important. The main research question is "How do persons conceptualize the experience of spinal cord injury over time?" According to Webster's Encyclopedic Dictionary of the English Language (1988), the term 'conceptualize' means to "form an idea or conception" of something. The purpose of this study was to identify the conceptions people formed of the experience of injury. Pratt (1991) defines conception as a "cognitive representation of something" (p. 10) and it was this definition that I chose to use in this study. He further exemplifies the term conception by suggesting that:

Individuals form conceptions of virtually every aspect of their perceived world, and in so doing, use those abstract representations to delimit something from, and to relate it to, other aspects of their world. Thus, conceptions are specific meanings attached to experiences or phenomenon which then influence behavior. (p. 10)

The word experience is used to indicate the act of living through, and involvement with, the event of spinal cord injury and its consequences.

This research project is premised on the understanding that the subjective ways in which individuals respond to their injuries are highly personal and influenced by objective factors such as length of time since injury, social and financial circumstances. These factors are crucial to how a person's disability will be experienced but to view adjustment to a disability in solely these terms would be overly simplistic. Oliver, Zarb, Silver, Moore, and Salisbury (1988) suggest that the complexity of the experience of spinal cord injury can be better understood by considering an intervening variable which they say can

be called 'meaning'. This variable has been further explicated by Oliver (1981) in the following manner:

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 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 arrived at as the result of interactions with other people, close relatives and friends and the public at large. (p. 51)

This qualitative study attempts to focus attention on this largely neglected variable by exploring the experience of spinal cord injury as expressed by individuals who have sustained the injury.

In this study spinal cord injury is seen as a significant life event rather than a personal tragedy. Integral to learning to assimilate this event into the fabric of life are the meanings individuals attach to the experience of injury. These meanings are unique to each individual and are formulated in the context of their personal and social environment. Some authors (DeLoach & Greer, 1981 and Vash, 1981) suggest that this learning process can be viewed as part of a larger process of psychological or spiritual development which, in some cases, can lead to the disability being transcended. The concepts of significant life event and psychological development do not imply a progression through a series of stages of adjustment but a re-evaluation of personal values, definitions of success and identity. Phillips (1985), in her discussion of the experience of disability, emphasizes the centrality of individual definitions of success. She considers that these definitions "are part of a

dynamic and even transformational process akin to a new individualism arising from the achievements of the disability rights movement" (p. 54). The educational model of rehabilitation provision is of necessity broad in its scope in order to accommodate a diversity of medical conditions and interventions. However, it became clear to me during the interviews that the subjects were describing a remarkable learning process which was not adequately addressed in, or informed by, current rehabilitation practice or the educational model of rehabilitation provision.

Underlying Theoretical Assumptions

In formulating the research problem, and in choosing the method used, I was influenced by a number of theoretical and conceptual assumptions which I will briefly discuss in this section as they relate to the development of this study.

In recent years the literature on spinal cord injury, particularly in the United States, has focused increasingly on psychological theories of adjustment to disability. These theories evolved from psychoanalytic theory, related to the treatment of mentally ill patients, and emphasized adjustment in terms of personality traits, motivation and interpersonal skills. Some theorists focused on the psychosomatic consequences of serious injury, that is the physiological changes and loss of body function and body image. According to these theories (Weller and Miller, 1977, Wright, 1983), persons with disability are assumed to undergo body image changes which represent a significant loss, and as a result experience a clinical depression. In order to come to terms with this loss a process of grieving or mourning is seen as essential. This

process has been broken down into a number of stages: shock, denial, anger, and depression, through which the individual is seen to move sequentially in order to become fully socialised and accepting of the disability.

To date, despite considerable criticisms (Albrecht, 1976, Oliver, 1981, Silver and Wortman, 1980, Shontz, 1984 and Trieschmann, 1988) the stage theories of adjustment have dominated research and clinical practice. The criticisms are based on two general issues. Firstly, these theories arise from an image conjured up by the theorists of what it would be like to become disabled, what Oliver (1981) calls "the psychological imagination" (p. 50). This gives rise to the 'personal tragedy' view of spinal cord injury which continues to pervade the health professional viewpoint. Spinal cord injury is seen as causing huge and permanent changes in a persons' life. In attempting to formulate an adequate conceptual framework for their research data Oliver et al. (1988) questioned this dominant view of spinal cord injury as a personal tragedy as difficult to substantiate and simplistic. They suggested that this viewpoint leads to the categorization of individuals into two groups; those who appear to cope or become 'successfully rehabilitated' and those who succumb to the tragedy. This gives rise, in their opinion, to the 'supercripple' phenomenon in which those who cope are ascribed with heroic characteristics, and who most closely approximate the functioning of an able bodied person. This role is not seen to fit those individuals who see themselves as ordinary people coping with extraordinary circumstances. Any individual response differences, any questioning or rebellion against the goals and methods of the rehabilitation service, which are primarily based on this

viewpoint, are seen as an individual inability to adjust to the injury. Secondly, adjustment is seen as largely an individual phenomenon, a problem for the person with disability and, as a consequence, the support group context and the wider social context are neglected.

The argument against the concept of adjustment is that it implies 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. It has been proposed (Oliver, 1981, Wright, 1983, Trieschmann, 1988 and Oliver et al., 1988) that data must be amassed on how individuals feel about their disability, their experience of the rehabilitation program, and what they actually do over a long period of time following discharge from the rehabilitation setting.

A number of sociological theories of adjustment to disability were developed which identified illness and disability as socially defined statuses or roles rather than as an individual problem (Shontz, 1984). These tend to treat the behavior of disabled persons not as responses to physical conditions or inner psychological states but as conformity to social norms which require the disabled to act in certain ways. Social environmentalists suggest that it is society which defines disability and puts pressure on the person with disability to accept personal devaluation. These theories, while drawing attention to the larger context of injury, neglect the inner experiences of the individuals.

The principle of normalization evolved out of a need to counter this devaluation or stigma. Sim (1990) tentatively defines the complex phenomenon of stigma as "representing a social identity characterized by the contravention of certain widely-held norms and values, and a consequent loss of social and moral worth in the eyes of both society

and the stigmatized themselves" (p. 233). The principle of normalization, in its North American form, affirms that the conditions of everyday life for people with disabilities should approximate the norms and patterns of the mainstream of society as closely as possible (Wolfensberger, 1980 and Wright, 1983). This principle stated in this way is deceptively simple. In reality it has many corollaries that affect not only the most clinical and direct services, but also the structural and systemic aspects of service systems. According to the proponents of normalization this principle is most powerful when applied to services to societally devalued people. Criticisms have centred on the clinical application of this principle which has focused on minimizing the differentness, or stigma of disability, that activates the perceiver's devaluation rather than on changing the perceptions or values of the perceiver (Wright, 1983, Phillips, 1985 and Sim, 1990). Strategies of normalization are particularly prevalent in the institutionalized rehabilitation process. The ideology of rehabilitation exerts patients to work hard at attempting to fulfil ordinary standards and strive to appear "normal" while at the same time teaching them that they are different (Goffman, 1987). Sim (1990) suggests that there is, "to some extent, an inherent conflict between attempts to assist normalization and the very process of rehabilitation" (p. 236).

More recently a number of theories (Wright, 1983 and Trieschmann, 1988), labelled integrative field theories, have been developed which view behavior as a function of the person in relation to the environment (Shontz, 1984). Trieschmann (1988), building on the work of Wright (1983), has developed a health care treatment model which she proposes facilitates the specific and effective

application of the educational model of health care delivery to rehabilitation. In her proposed model the behavioral equation for rehabilitation success is $B = f(P \times O \times E)$ where outcome behavior (B), health, and rehabilitation adjustment are a function(f) of the interaction of the psychosocial (P), biological-organic (O), and the environment (E) factors. Behavior in this model represents three categories of outcome behavior: survival activities, harmonious living, and productivity. Promoting function in outcome behavior is brought about through an understanding of the interactive nature of these three categories.

Adjustment is here seen, not as a static condition with a definable start and end point, but rather as "a fluctuating phenomenon in any of our lives, and at any time it is the result of having achieved a balance among three major influences: our psychosocial resources, our biological-organic state and our environment" (p. 27). This redefinition of the concept of adjustment clearly expands beyond the traditional focus on the physical and functional aspects of rehabilitation. In this way, Trieschmann draws together the more global educational approach, as opposed to the traditional medical model of health care delivery, and an expanded model of adjustment to disability which takes into account the psychosomatic, personal, social and environment factors which impact on adjustment.

Central to these latest theoretical developments is the understanding that it is not the physical dimensions of the disability which ultimately dominate but the psychosocial issues of living with the disability in one's own environment for 30-50 years. Also integral to this approach is an expanded time frame during which individuals

become socially adjusted in terms of both personal responses and external circumstances.

Oliver et al. (1988) have developed the concept of disability career. This concept incorporates the complex relationship between the individual, the social and material context within which the disability occurs, and the meanings attributed to the experience by the individual. A career in disability refers to the course or progress through life of a person with disability, the training needed to pursue the career, the problems, conditions and even benefits related to the disability. The 'career' concept is useful as it facilitates consideration of the injury over time and not just as a single event (Blaxter, 1980).

The idea of disability viewed from the perspective of a lifetime has resulted in some authors using 'significant life events' as the conceptual framework of their research. Dohrenwend and Dohrenwend (1974) suggested that the important characteristic of a life event is that it should not necessarily be distressing or negative, but that it should be disrupting or have the potential to disrupt. That spinal cord injury constitutes a significant life event is beyond question. The question rather becomes how the individual incorporates the event into the context of their life and the meanings which are attributed to it.

The opportunity to address this question, and others related to the individual experience of spinal cord injury and its resulting disability, has been largely denied the health professionals working in the systematic provision of rehabilitation services. Persons discharged from the rehabilitation setting are not followed up in a systematic way and rarely return to share their experiences in the years post injury. Consequently, health professionals continue to hold views founded on

the model of spinal cord injury as personal tragedy, and plan rehabilitation programs based on the expected functional capabilities of a particular level of injury. It is becoming apparent that these views do not reflect the reality of life after a spinal cord injury, and the stereotyping inherent in this approach to rehabilitation serves only to widen the gap between, what the people feel they need, and what rehabilitation services are able or willing to provide.

The Study

The subjects involved in the study were all individuals who had sustained a traumatic spinal cord injury between three and five years ago. The criteria for inclusion in the study were that the individuals had sustained a traumatic injury, had been discharged from the rehabilitation centre, and were within five years post injury. The subjects were selected initially through a contact person with spinal cord injury who is currently working as a social worker in the community and at the rehabilitation centre.

Data collection took the form of indepth interviewing. The questions asked were open ended and deliberately non-specific in an effort to trigger accounts of meaningful aspects of the experience identified over time. The presentation of the research results are based on the subjects' responses to the questions, and commonalities and differences in those responses which were identified through in-depth analysis of the data.

The methodology for the study was qualitative and descriptive. I chose this approach because of the absence of similar research related to spinal cord injury, and because it allowed me to explore the

experience of spinal cord injury, beyond the rehabilitation setting, from the perspective of the people who had themselves sustained the injury. The research is essentially exploratory. This study is seen as a phase in a line of inquiry which will lead to the development of concepts about the learning strategies developed by people experiencing the long term consequences of spinal cord injury.

Assumptions

The following assumptions were made in the study:

1. The qualitative approach is congruent with the purpose of this study.
2. It is important that health professionals in rehabilitation have an understanding of the individual's experience of the long term consequences of spinal cord injury, and that understanding be achieved through thorough documentation of the individuals' perspectives.
3. Individuals develop strategies by which they learn to adjust to the disability resulting from spinal cord injury and which give meaning to their experience. These strategies can be identified through indepth interviews and dialogue with individuals over time following injury.
4. That "successful rehabilitation" can be defined only by the individuals who are experiencing the consequences of spinal cord injury and is greatly influenced by their individual resources, social and physical situations.
5. The subjects' version of past events is taken as being accurate. No attempt was made in this study to compare this information with documental evidence or the accounts of others.

Researcher Bias

Through reading, professional practice and personal contact in the field of rehabilitation I began to identify a number of issues evolving from the discrepancy between the perspectives of spinal cord injury held by health professionals and those held by 'patients.' The skills taught and information provided in the rehabilitation programs did not seem to adequately address the needs identified by individuals after discharge from the facility. There is no follow up system in place for people with spinal cord injury so essentially they are on their own when discharged home. Patients felt that while being taught to accept responsibility for their own care the rehabilitation bureaucracy treated them like children rather than adults. My interest in developing this research project stems from the gradual recognition of these issues. These issues represent what Hammersley and Atkinson (1983) refer to as "foreshadowed problems" (p. 28). Malinowski (cited in Hammersley & Atkinson, 1983) considers "foreshadowed problems to be the main endowment of a scientific thinker" (p.29), being the result of theoretical studies and acquaintance with the latest developments in a field, and not to be mistaken for preconceived ideas, which in his opinion are pernicious in any scientific work. Preconceived ideas are seen as inflexible and rigid views held by the researcher which are antithetical to the reflexive process operating throughout each stage of a qualitative project. Particular care was taken to ensure that these issues, whilst representing the motivation for this study, did not overly direct the questions asked in interview or limit the analysis of the data.

No attempt was made to represent myself as a neutral observer in the interview process. I was an active participant engaged in the

process with the subject. Consequently there were times when I deemed that the topics being discussed were of too intimate a nature and therefore inappropriate for inclusion in the study. My eclectic interest in the consequences of spinal cord injury and the mechanisms of coping, described by the subjects, at times became focused on details of physical functioning which were not relevant to this study. My past involvement as a physiotherapist was known to the subjects. This knowledge may have generated an assumption on the part of the subjects that I was predominantly interested in the physical functioning aspects of the injury, for example, their spasticity status or wheelchair preferences. These same biases, however, enabled me to acknowledge the depth and breadth of the individual's experience beyond the physical ramifications, engendering a level of trust which would otherwise have been missing. Through this same experience I was able to elicit the quality and depth of the data revealed by the subjects.

Scope and Delimitations of the Study

The scope and delimitations of the study were as follows:

1. The focus of this multi-subject study was the collection of descriptive data on the individual perspective of the experience of traumatic spinal cord injury.
2. This study relies almost exclusively on one data source, that is, the interview transcripts.
3. The findings of this study are specific to the subjects and as such are not generalized to the population of people with spinal cord injury. A number of conceptions of the subjective experience of spinal cord injury over time have emerged through examination of the data. These

conceptions have been grouped and documented under three thematic categories. All the subjects defined themselves as 'successfully rehabilitated.' It may, therefore, be possible that the concepts identified by this group could be shared with others who define themselves in the same way.

4. The data collection was limited to one interview with each subject.
5. The data was both limited and enhanced by the subjects' perception of the purpose of the interview, memory of past events and choice of answer content.
6. The data may have a positive content bias due to a subconscious effort on the part of the subjects to present their life in as positive a light as possible.
7. The purpose of this study was not to test a hypothesis or to develop theory, but rather to formulate the emerging conceptions in more general terms with the purpose of exploring them in relationship to adult education theory and facilitating further research development.

Significance of the Study

There is a paucity of literature in the field of rehabilitation medicine examining in depth, individual experience of spinal cord injury and its consequences over time. The existing literature has focused on the provision of rehabilitation services in an institutionalized setting. Successful rehabilitation has been defined in terms of the skills or behaviors acquired which facilitate functional independence. The overwhelming focus of literature on psychosocial issues has been the stages of psychological adjustment. There is an increasing awareness that these approaches have a number of inadequacies and fail to

encompass the complexity and the dimension of time involved in adjusting to a disability. The proposal of this study is that research which facilitates access to the individuals perspective of the experience of spinal cord injury will provide valuable information upon which to review and base provision of rehabilitation service. Exploration of this vital perspective would increase understanding of the adjustment over time and, if the knowledge were to be integrated into the planning of rehabilitation services, would facilitate bridging the gap between services offered and perceived need.

The educational model of health care provision has been identified as more appropriate for teaching health care behaviors, particularly to those with physical disabilities. This may serve as a useful model for developing more effective strategies within the rehabilitation setting but the proposed implementation still fails to take into account the social context, meaning to the individual, and the dimension of time. Learning to live with a disability, if we accept Trieschmann's (1988) suggestion that adjustment starts at the moment of injury and continues for the remainder of a person's life, may be a lengthy and frustrating process. One of the underlying assumptions of this study is the concept of 'significant life event.' Within this framework spinal cord injury can be viewed as an event requiring incorporation into the natural adult development which is not curtailed because of the injury. In broadening the analysis of the data with respect to the adult education theories of learning through change and crisis, and in particular Mezirow's theory of transformative learning, this study may influence the educational approach and learning strategies utilized in the provision of rehabilitation service.

Organization of the Thesis

In Chapter Two the literature related to the meanings attributed to the experience of spinal cord injury and the learning strategies employed following an injury of this nature will be reviewed. The research methodology will be discussed in Chapter Three with particular attention being paid to the methodological decisions I made during the research process and my role as researcher in that process. The data and the emerging concepts which have been identified will be presented and discussed in Chapter Four. In Chapter Five I will attempt to show how a theory of transformative learning and the data analysis results can each be informed by the other. To conclude the study, findings will be integrated and compared with the findings of the literature, and the implications of an alternative educational approach for rehabilitation practice discussed in Chapter Six.

Chapter Two: REVIEW OF THE LITERATURE

The purpose of this literature review is to identify, define and elaborate, where possible, upon the principal topics which are relevant to this study. Learning to live with the disability resulting from a spinal cord injury may be a lengthy and often frustrating process. The complexity of this process has not been addressed by the practice of rehabilitation medicine, or the associated literature, both of which are dominated by the medical model approach to acute disability management and research, that is, focus almost exclusively on the physical dimension of the problem and on quantifiable outcomes.

The importance of the psychosocial issues of living with a disability are gaining recognition and this is reflected by the use, often synonymously, of such terms as adaptation, adjustment, coping and rehabilitation. These terms will be defined from the perspective of their influence on research and their use in the literature. Adjustment to spinal cord injury research continues to focus on the hospitalization phase and the role of health professionals. The literature reporting studies of individuals' subjective assessments of aspects of the rehabilitation process have been focused predominantly on injury as personal tragedy and the stages of adjustment model.

The medical model of health care service provision is being superseded by an educational model which emphasizes the active participation of the individual in developing appropriate behaviors related to health. The effective application of this model to rehabilitation programs may be enhanced by a number of theories of adjustment which view behavior as a function of the person in relation

to the environment. Spinal cord injury may be perceived as a significant life event which has a disruptive effect on life but from which an individual over time can recover. The personal dimension of rehabilitation, as interpreted by those persons who have experienced it has, as yet, received inadequate attention. This dimension may be explored through the application of qualitative methods. This review includes a brief discussion supporting the use of a qualitative approach to the collection and analysis of data describing the experience of spinal cord injury, as conceptualized by individuals, who consider themselves to be successfully rehabilitated. If spinal cord injury is approached from the perspective of significant life event or crisis, the process of adjustment to the resultant disability may be seen as a unique and complex learning process.

Definition of Terms

Adaptation

The concept of adaptation originates from the study of biological evolution so that as the demands of the environment change so do the individual's needs. White (1974), a psychologist, has proposed that adaptation consists of strategies which, in turn, are made up of a repertoire of behaviors employed by the individual in interaction with the environment. He describes three elements considered essential to the behavior that results in adaptation: The individual must have the appropriate amount of information about the environment, be able to process information and act upon it, and maintain a sense of autonomy and freedom to act. Adaptation is an active process, engaged upon by the individual within a specific context, for the purpose of survival and

development (McCuaig, 1988). Adaptation may change depending on situational factors, the people involved, the physical environment, whether the strategy is used over a short or long time period, and the degree of risk involved. Most commonly adaptation is used as a descriptive word in conjunction with equipment, action, the environment, and behavioral responses (McCuaig, 1988). Cohen and Lazarus (1983), however, place adaptation in the psychological domain and describe it as a broader concept than coping. According to their description adaptation involves routinized behavior, what people do, the repertoire of behaviors they create to deal with both the minor and major challenges in everyday situations, not just how they react cognitively.

Coping

White (1974) differentiates coping from adaptation on the basis of the nature of the situation being faced. Coping is described as a response to an acute or unusual event or circumstance in an individual's life. The emotional response to traumatic spinal cord injury may be viewed as a stress response of major proportions resulting in a disturbance of the person's emotional homeostasis. Restoration of this homeostasis requires coping responses or adaptive responses (Ben-Sira, 1981 and Trieschmann, 1988). Cohen and Lazarus (1983) describe coping as a process, rather than a trait, by which an individual manages internal and external stress, irrespective of outcomes, and possibly altering over time. It has been suggested that coping is a necessary precondition for being sufficiently motivated to engage in the efforts of physical rehabilitation.

Ben-Sira (1981) identifies two dimensions of coping (1) the state of coping which relates to the functional component of rehabilitation and (2) the perception of the coping as successful by the individual. This second dimension begins to address the importance of the individual's personal judgement of coping as separate, and frequently different, from the judgement of others. Other authors (Adam & Lindeman, 1974) describe coping mechanisms as the ability to maintain self-esteem, the successful acquisition of new models of lifestyle after being disabled, and the ability to access information on groups who support a new set of roles, values and goals. Thus facilitating, teaching or assisting persons to develop appropriate coping mechanisms is an integral aspect of a rehabilitation program.

In the final analysis the best definition may well be provided by an individual who has experienced first hand coping after spinal cord injury. In his book Options: Spinal Cord Injury and the Future (1980) Barry Corbet speaks of coping:

One dilemma was obvious: to cope or not to cope. To cope meant to work and play and live and love as if nothing had happened. But something had happened. Not to cope meant to refuse responsibility for personal health and welfare, to allow physical and psychological complications to bankrupt rehabilitation. Suicide was even considered, and nobody knew for sure if that was coping or not coping. All the options seemed lousy. (p. 5)

Adjustment

Coping with affective problems may be viewed as a goal of adjustment which is in itself seen as a goal of rehabilitation.

Rehabilitation, however, is not synonymous with the concepts of adjustment, coping, happiness or vocational productivity. Trieschmann (1988) suggests that perhaps the word "adjustment" should be eliminated since its use may entail a value judgement on the part of the "rehabilitator" as to what the "rehabilitatee" must do to be adjusted. Furthermore the concept of adjustment may imply that it is an all-or-nothing phenomenon with a definable endpoint and applicable to everyone equally, where in fact, it is not a static state that can be measured at some point, and it cannot be defined in the same terms for everyone.

The signs of adjustment are considered by Cohen & Lazarus (1983) to be the capacity to sustain a high quality of life and function effectively on a social level. Such a state represents a transformation (pre-disability to post-disability) in the way a person sees himself. Overcoming the life-threatening aspects of the injury and learning to perform the routine tasks of every day life are elements of physical adjustment. The psychological dimension or emotional adjustment, particularly how the individual sees himself, and how he presents himself to others, is considered the most crucial indicator of achievement of rehabilitation goals by some authors (White 1974, Ben-Sira, 1981, and Cohen & Lazarus 1983). Self-perception and self-acceptance are believed by these authors and others (Zola, 1981, Trieschmann, 1988, and Oliver et al., 1988) to have a greater influence on social adjustment than physical ability or appearance. The discussion of adjustment following traumatic disability has been dominated in the past by a variety of theories of stages of adjustment (Weller & Miller, 1977, and Wright, 1983).

A major interest among researchers has been on the process of coping with undesirable life events and the role rehabilitation programs have to play in that process. Consequently data collection efforts have been focused on that period of time immediately following the event. As a result a great deal has been learnt about the individual's attitudes, feelings, and the coping mechanisms they use during the period of time when the level of experienced stress is likely to be high. Examples of this approach are the studies of Bulman and Wortman (1977) and Weller and Miller (1977), which are frequently cited in support of the stage models of emotional response.

These and other works have been reviewed by Silver and Wortman (1980) and Trieschmann (1988) who concluded that little evidence has been provided to show that stages of psychological adjustment do occur. As Trieschmann (1988) notes "each of the descriptions of stages of adjustment is based on the clinical impressions of the particular author, and that no data have been presented in any articles to demonstrate reliably and validly the existence, sequence, or duration of these stages" (p. 69). In their opinion, the difficulties involved in formulating a clear conceptual definition of effective coping, and an interpretation of the data strongly biased by expectations based on implicit stage theories, have hindered potential advancement in this field.

Adaptation, coping and adjustment, for the purpose of this study, are seen as components or goals of the rehabilitation program. They are interrelated concepts and, without question, would be defined differently by each individual who sustains a spinal cord injury. Failure to recognize these differences leads the health professional to develop

preconceived ideas about the psychological reaction to spinal cord injury, and the roles that patients should adopt during the rehabilitation program.

Other Issues in Rehabilitation

Stereotyping

Albrecht and Higgins (1977), in their early study on rehabilitation success as adaptation to a rehabilitation service, comment about staff reactions to patients who do not adopt the traditional sick role, and suggest that staff perceive more psychological suffering than people with spinal cord injury describe. In addition, this bias may reflect an expectation that the staff has about expected responses to spinal cord injury as based on the stages of adjustment model. Typically, when patients formulate innovative plans, solutions and alternatives appropriate to their own contexts such plans are usually labelled 'unrealistic' by rehabilitation experts regardless of their degree of 'functionality' for the person. This labelling is particularly evident when the responses to disability, plans and alternatives do not conform to the stereotyped role of the disabled, or to the system of values pervasive amongst health care professionals.

Roth (cited in Albrecht, 1976) suggests that goals and solutions arrived at by health professionals serve to keep the disabled constrained within the role reserved for the disabled as a category, and to discourage any significant deviations from it, labelling such patients as non-compliant, 'difficult' and 'poorly motivated'. Inherent in the professional-client relationship is the commonly assumed client's lack of knowledge and ineffectiveness in coping with the problems caused by the injury. Ben-Sira (1981) suggests that dependence on a professional

implies power over that client, and that motivation becomes synonymous with the goals of rehabilitation as defined by the professionals in terms of level of injury, functional outcome, expectations and visible results. Paradoxically, in learning to function within the rehabilitation agency, the individual is encouraged to be dependent and to sublimate self-definitions of successful rehabilitation. Involvement in the system, Ben-Sira (1981) suggests, carries the potential of dependence rather than success and a consequent sense of failure upon discharge from the system. Disabled persons can be conceptualized as a minority or disadvantaged group aspiring to achieve as 'normal' a life as possible (Safilios-Rothschild, 1981 and Sim, 1990). There has been little information available on self-definitions of successful rehabilitation. Without gathering sufficient direct information from their target populations professionals assume the authority to decide the fate of underprivileged people (Safilios-Rothschild, 1981).

New awareness among persons with disability has produced some eloquent biographical statements, for example, Kriegel (1969), Jones (1972), Goldiamond (1976), Corbet (1980), Zola (1981), Murphy (1987) and Callahan (1989). Sufficient self-esteem and self-confidence is being generated to enable individuals to question, demand and protest the status quo. For persons with disabilities the dilemma of "trying harder to succeed" has been driven by success as defined by others. Questions have been posed, such as "does success mean the pursuit of normalization, or even the illusion of normality at all costs?" or does success mean "becoming a professional handicapper" (Phillips, 1985, p.45) that is, becoming an individual known primarily for the disability (Safilios-Rothschild, 1981, Shearer, 1981 and Phillips, 1985)?

Normalization

The principle of normalization was conceived in Denmark in the Fifties as part of a movement to "let the mentally retarded obtain an existence as close to the normal as possible" (Wolfensberger, 1980, p.7). The most extensive elaboration of the principle was published as a text in the Seventies by Wolfensberger in which he tried to adapt the principle so that it would be applicable to all health care services. The principle is based on the idea of disability as deviant. Deviancy, according to Wolfensberger (1980) "is not within the person; it is within the imposed social roles, the values, and the perceiver's interpretation" (p. 13). The essence of the principle of normalization is that "deviancy can be reduced or eliminated either by a) changing the perceptions or values of the perceiver or b) minimizing the differentness or stigma of deviancy that activates the perceiver's devaluation" (Wolfensberger, 1980, p. 13). It is the latter that has influenced rehabilitation practice, and contributed to the traditional and stereotyped definitions of success, which have placed the onus on the person with a disability to adapt to the dominant majority. It is this ideology which underscores the attitude of injury as tragedy, and perpetrates the labelling of those individuals who break out of the mold, that is, pursue life as pre-injury, as 'supercripples' (Shearer, 1981). Thomas (1982) says:

I am persuaded that one of the failures of our society is not its' treatment of the disabled person (though there are wide gaps and inequalities here) nor its' lack of sensitivity to needs... but its' failure to comprehend the normality of handicap. It is the overwhelming insistence that we perceive and encourage 'the disabled' to perceive themselves as deviant that is the root of the problem. (p. 175)

Self-definitions of successful rehabilitation

The primary goal of rehabilitation has been traditionally seen as making people with disabilities as independent as possible, and that the recipient of rehabilitation leaves the formal setting fully rehabilitated. These notions are being challenged. The professionals' definition of successful rehabilitation varies according to different therapeutic perspectives. From a psychological perspective the individual is successfully rehabilitated when the flexibility and skill to enter comfortably into a variety of dependence relationships is achieved (Kerr & Mayerson, 1987). Cogswell (1984) sees the processes of socialization by which individuals acquire new roles and the development of new self-definitions, skills, activities and associations as central to rehabilitation success. Measures of rehabilitation success in health care, however, continue to focus on the functional or instrumental components of rehabilitation, for example, returning to home and predisability lifestyle (Ben-Sira, 1981), performance of general selfcare activities, economic independence, employment, and the type and level of social interaction.

The question needs to be asked "who should be the judge of successful rehabilitation goal achievement?" Each individual possesses assets, liabilities, and a value system which have relevance to their life, all of which influence the course of rehabilitation after injury. Since people following spinal cord injury need to be taught to cope with their own unique situations it is important to consider where they came from and what each has lost. All too often values are imposed and goals set, without consulting the people directly involved, and which have little relevance to the environment to which they are returning. To the extent

that successful rehabilitation implies both the will to cope, and adjustment to the 'normal' environment, the individuals' subjective perception of their condition, that is self-conception, becomes crucial. One person recounting her experience in Shearer's (1981) study described successful rehabilitation as "the experience of accepting responsibility for my own life and creating a life worth living, giving me a sense of self-reliance, self-confidence and the belief that I can take care of myself" (p. 19).

It seems clear that these self-definitions are entirely unique to each individual, that formulation of the definitions is complicated by rehabilitation professionals' objectives of normalization, and that these objectives are frequently inconsistent with the individual's personal expectations and goals (Wright, 1983, Phillips, 1985 and Trieschmann, 1988). Phillips (1985) uses acquiescence and normalization as examples of traditional definitions of success. Subjects in Phillips' study shared with her, through oral narratives, their experiences of the rehabilitation program and their individual determination of success. Informants indicated that for the most part they respected their rehabilitation practitioners as individuals, but they were ambivalent about the perceived goal of rehabilitation namely the emphasis on normalization rather than on potentiation. From their narratives Phillips identified "five major kinds of success: acquiescence, normalization, adaptation, renegotiation and inversion. The first two [being] invoked for social success, and the last three for personal success" (p. 46). These results appear to suggest dynamic approaches to definitions of success, that individuals did not subscribe to one definition, but invoked definitions for their congruence with specific personal or social situations. In this

way, Phillips (1985) concludes, "these definitions of success are part of a dynamic and even transformational process, by which the individual attempts to assert control over the unique disability related experiences" (p. 46). Studies such as this one, in which the experience of disability is explored from the perspective of the individual, have much to contribute to future research in rehabilitation.

Rehabilitation Research

Ben-Sira (1981) suggests that "in spite of the generally recognized centrality of psychological adjustment, physical and functional recovery continue to be conceived as the ultimate goal of rehabilitation" (p. 565). Despite awareness of the significance of the individual's assessment of the consequences of disability and their management in successful rehabilitation most of the criteria of rehabilitation and hence the focus of research concentrate on the rehabilitation professionals' judgements. These judgements are commonly viewed as 'objective' compared to the 'subjectivity' of the former.

The Quantitative Approach

In accordance with this view the quantitative approach to research has been the most frequently used method in the health care fields (Kielhofner, 1982). The purpose of this type of research is to examine relationships among variables usually in an attempt to detect or confirm causality. It utilizes experiments in which independent variables are manipulated and dependent variables are observed for possible changes. Changes are measured by specific instruments, data are collected by surveys, questionnaires or experiments, and the

analysis is conducted using statistical procedures. Results of these procedures are determined to be statistically significant or insignificant and a conclusion drawn as to the nature of the relationship among variables or to the effect of the treatment administered (Hultsch & Deutsch 1981, and McCuaig, 1988). The intent of such scientific and controlled experiments is to reduce the focus of the research by controlling the variables and confounding factors so that the impact of one variable on another might be discovered. Marton (1981) describes this research approach as a "first-order" perspective that orients itself to the world and makes statements about it.

This methodology, designed for highly scientific laboratory experiments, is not always the method of choice for the collection of descriptive data on an individual or group within the context of a specific environment. Traditionally, medical research has focused on the generation of empirical data which suggest that rehabilitation therapies are delivered in formal, time-limited units in which the person is the passive recipient of instructions and guidelines from the professional staff. This is a truly limited view of the complexity of the rehabilitation process. Trieschmann (1988) is of the opinion that formal therapies permit little behavioral independence or zest and the number of behavioral and time frame options available to the person are limited. She further suggests that rehabilitation medicine, with its emphasis of helping people live more satisfactory lives, is considered "a weak science," and as a consequence, has been pressured to adopt quantitative medical research approaches with their emphases on accountability, measurability and objectivity in data collection.

Adjustment in the rehabilitation setting

Traditionally, rehabilitation has been concerned mainly with maximising general health and physical independence and returning the individual to gainful employment. It continues to be limited by formalized facility programs and the service delivery orientation of health professionals. Smith (1979) has described the rehabilitation process as a sequence of events associated with the passage of an individual from the onset of illness to recovery. He suggests that the process involves three primary stages (1) illness behavior (2) treatment and (3) restoration. Implicit in this description is the assumption that the adjustment process occurs within the formalized rehabilitation setting.

Lawson's (1978) elaborate longitudinal, multimeasure study centred on depression as counterproductive to rehabilitation. It involved 10 patients with high level spinal cord injuries who were studied for five days of the week for the entire length of hospital stay. Four measures of depressive affect were used; (1) self report (2) ratings by staff (3) behavioral measure of verbal output and (4) an endocrine measure - 24 hour output of urinary tryptamine. Statistical analysis of the data obtained resulted in the derivation of 44 categories of significant events and showed a discrepancy between the assessments of these events made by patients and the health professionals. Although other emotional reactions were not assessed in this investigation, the results suggest that all spinal cord injured patients do not experience a stage of depression during their adjustment to permanent disability.

More recent studies by Rosenstiel and Roth (1981) and Richards (1986) targeted changes in cognitive activity and psychologic adjustment during rehabilitation and the first year after discharge. In analyzing their data Rosenstiel and Roth (1981) identified certain trends in cognitive activity related to adjustment to disability. These trends included rationalization and denial in anticipating going home, avoidance of worrying or catastrophizing about what life would be like, concentration on personal goals for after discharge, and mental rehearsal for discharge. In their view, the most striking trend is that contrary to common beliefs, denial and rationalization are not necessarily negative coping processes which lead to a negative outcome, but may be successful coping processes which, in some situations, for some individuals lead to a positive outcome. Although the small sample size can hardly be considered conclusive, this study gives us some interesting ideas on the concept of coping which could lead to further research.

In Richards' (1986) study subjects completed a structured questionnaire at regular three monthly intervals and the Beck Depression Inventory, Wiggins Hostility Scale and the Handicaps Problems Inventory were used as outcome measures. Moderately increased depression and hostility in the spinal cord injury group, compared to an able bodied control group, were found immediately post-discharge, but these differences were gone in a year. On a specific measure of adjustment to disability the spinal cord injury group showed significantly increasing comfort with disability status over the same period. Richards concludes the severity of psychological adjustment

difficulties may have been overestimated and that problems appearing immediately after discharge appear to resolve rapidly.

Dewis (1989), using a qualitative research design, sought to investigate the meaning of body changes from the perspective of the injured persons and to describe the strategies they used to respond to the changes. It was found that the behaviors of the subjects focused on a concern with feeling 'normal' and being valued, and the use of deliberate strategies that helped to engender positive feelings in this regard. "Efforts to normalize were consistently seen in three areas: physical appearance and function, physical and emotional independence and social skills and interpersonal relationships" (p. 389). Dewis noted that the strategies used to maintain normalcy were ingenious and resourceful and were, for the most part, developed by the subjects without direction, or in some instances, approval from health care professionals.

These studies, which investigate a limited range of possible factors influencing adjustment, taken collectively support the view that the rehabilitation process is a highly individualized and complex one, and that application of a stage model of adjustment is inadequate to address the complexity of responses. They are also supported by the findings of some earlier studies, for example, Willems (1976), Rogers and Figone (1979), Zola (1981, 1982) and Caplan (1983) which have shown that rehabilitation staff, who have frequently been called to make assessment or judgement of an individual's adjustment status, consistently overestimate the degree of psychological stress felt by the patients.

Shontz (1984) drawing from his experience in rehabilitation, developed a general model of reaction to crisis and undesirable life events as an alternative to the stages of adjustment model. He describes this reaction, which follows the initial shock, as one of encounter. Reality is confronted and the individual experiences a profound helplessness, disorganization and panic. During this phase reality may seem overwhelming and the individual is aware of an inability to plan, reason or engage in active problem solving to improve the situation. Shontz (1984) characterized the adaptive sequence as a continuous shifting between encounter and retreat, that is, a denial of the existence of the injury. In his opinion retreat provides a "base of operation from which forays into the future can be made and to which the person may withdraw for safety if they fail" (p. 172). The emphasis is placed on the value of gained experience, as a result of which, these cycles of encounter and retreat become progressively less frequent over time as mastery over the injury and its consequences is achieved.

Albrecht (1976) and Trieschmann (1988) provide an overview of the stage theories of adjustment and the research claiming to support them. Treischmann draws the following conclusion: "each of the preceding descriptions of stages of adjustment is based on the clinical impressions of the particular author, and that no data have been presented in any of the articles to demonstrate reliably and validly the existence, sequence, or duration of these stages" (p. 69). Rehabilitation programs continue to emphasize physical aspects of rehabilitation often to the exclusion of psychosocial concerns (Trieschmann, 1988). MacDonald and Forman (1987) suggest that rehabilitation facilities experience ongoing problems with patients who are non-compliant,

disruptive or not benefiting from the programs and services offered. The literature suggests that psychosocial problems are minimally acknowledged in rehabilitation treatment programs. The continued adherence to the stages model of adjustment by health professionals despite the research and opinions which refute it, widen the gap between the reality as perceived by health professionals, and that perceived by individuals experiencing spinal cord injury.

The long-term perspective of adjustment

Research, directed by the framework of the stages of adjustment models and an emphasis on personality traits as predictors of successful rehabilitation, has primarily focused on the relatively short term perspective of adjustment to the injury. Consequently, research efforts have failed to address the changes experienced by an individual over time and the many other factors which impact on adjustment to disability. Research to date suggests that causal relationships among variables, predictors or indices of successful adjustment, such as, locus of health control, self-concept, absence of somatic complaints, cooperation with rehabilitation regimes, and resumption of social and vocational activities, are likely to be complex and multidirectional.

There is a growing acknowledgement that the process of adjustment occurs over a period of many years. Earlier authors cited two years as being the optimum length of time required to rediscover a sense of 'normal' pattern in life (Carter, Kerr & Thompson, and Gordon, cited in Trieschmann, 1988). Corbet (1980) provides 54 biographies of individuals with spinal cord injury who describe the evolution of their lives since the onset of the injury. There is a striking diversity in these

accounts regarding perceived quality of life and length of time required for adjustment. In researching how persons with severe disability perceive the effects of their disabilities on their lives, Weinberg and Williams (1978) discovered that 60 percent of their subjects (eighty-eight subjects of which 30 percent had spinal cord injury) thought of their disabilities as a fact of life or an inconvenience, while only 7 percent thought their disability was the worst thing that had ever happened to them. In fact, 49 percent thought their disabilities had certain advantage. In response to the question that if they had one wish, would they wish they were no longer disabled, 49 percent said yes, 51 percent said no. There was no significant correlation between type of disability and subjects' responses.

These results suggest that the subjects reframe the disability within the context of their lives and that their perceptions of disability differ significantly from those held by health professionals and able bodied persons. Woodrich and Patterson (1983) report that with increased length of time post-injury there is increased acceptance of the disability. Cook (1982) found that a group of persons, who had been injured several years, described their current lives as 'better,' as having more quality, than their lives prior to the injury, which contrasted with how they rated their lives soon after onset. Oliver et al. (1988) are of the opinion that, if conditions in society and the provision of follow up services and support were improved, the process of social adjustment might not take an average of 9 years as the results of their study appear to suggest. Silver and Wortman (1980) conclude their review of the research pertaining to adjustment to an undesirable event by saying "in the light of the evidence that life crisis may have impact on an

individual for a considerable period of time, long-term follow up is clearly desirable" (p. 330).

Trieschmann (1988) reiterates that the terms 'adjustment', 'success', 'coping' and 'rehabilitation' are difficult to interpret and there is no agreement to date on their meanings. To avoid the errors inherent in methodological bias, judgement and interpretation, she proposes that data be gathered on what people actually do following the formal rehabilitation phase, and how they feel about the disability over time. In acknowledging the individual with disability as ultimately the most knowledgeable person, researchers could assist in the integration of the physical, psychosocial and personal dimensions of rehabilitation to the benefit of both the individual and rehabilitation practice.

Recently the trend has been to emphasize the variability in responses to spinal cord injury and thus challenge the assumptions inherent in the stage theories and the medical model approach to rehabilitation. A review of some recent studies demonstrate this trend but also reveals the limitations of the research methods used, and the diversification which occurs when research is focused by specific professional disciplines e.g. psychology, sociology, medicine, nursing and occupational therapy.

Socialization as part of the rehabilitation process was studied from the individuals' perspective by Cogswell (1984). Little detail is given about the method involved in this study although the results are descriptive in nature. Interviews appear to have been conducted over time after discharge from the rehabilitation setting. Persons with spinal cord injury were asked what they did, whom they saw, how they responded to people and how others saw them in social settings.

Comparison of these experiences provided information about the socialization strategies employed by the individual over a 1-3 year period of time, and the insufficient contact with an experienced peer group with whom a benchmark of progress could be established. To Cogswell the subjects appeared, early in the rehabilitation process, "to have a diffuse image of the final goal - reintegration into the community - as persons of independence and worth and seemed unaware of the long range process they were embarked upon" (p. 154). During the first two years after injury they appeared to organize their socialization in response to day to day problems, avoid situations where negative social responses could destroy their positive definitions of self, and sought social situations where demands were not beyond their current level of competence. This period of time, in contrast with the structure provided in the rehabilitation setting, was often seen to lack meaning with few professional or peer resources available.

Koehler's (1989) study was based on the hypothesis that a strong relationship exists between self-concept and successful rehabilitation. She tested this hypothesis with a large group of individuals with spinal cord injury readmitted and receiving treatment at several rehabilitation centres, and who were an average of 17 years post injury. The measure of self-concept used was the Tennessee Self-Concept Scale. In her conclusion Keohler suggests that there are basic personality factors whcih facilitate or hinder individuals' ability to change their lifestyle.

These conclusions are supported by the results of a study by Frank and Elliott (1989). This study was based on the premise that individual beliefs about control over health contribute to successful adjustment. The subjects were, similiar to the previous study, inpatients

in a rehabilitation facility at the time of the study but had experienced their injury an average of four years ago. The Multidimensional Health Locus of Control Scale, and the Beck Depression Inventory were used as measures. The authors concluded that personality characteristics such as independence, risk-taking, impulsiveness and an internal locus of control belief contribute favorably to adaptation and adjustment to disability.

Most of these studies tend to identify a personality characteristic of interest to the researcher and assess its presence or absence in the spinal injury group at hand. Whilst dispensing with the issue of stages of adjustment as the acknowledged style of coping for all people with spinal cord injury they fail to explore the steps people do undertake to meet the challenge of this injury. It seems apparent that the health professional approach is divorced from the reality of coping with the injury, that emotional responses, such as, depression occur infrequently and that often the response is an action oriented, skill attainment one. These studies are limited also by the quantitative methodology employed which is driven by the hypothesis posed, and the psychological instruments used, and fail to capture the complexity and variation of response to the injury. The emphasis on individual personality traits remains. These traits are examined in isolation from the social context and other factors which impact on adjustment. This approach derives from the philosophy which places all responsibility for success on the individual with the disability and which is central to the medical model of health care delivery.

The complexity of adjustment, and definitions of successful rehabilitation, are beginning to be reflected in studies which set out to

explore long term adjustment using a combination of direct behavioral observation, interviews and psychological test data in order to assess individual responses to spinal injury. One such study (Green, Pratt and Grigsby, 1984) was designed to assess "self-concept among persons with long term spinal cord injury". The mean duration of injury was 11 years and a standardized self-concept scale and questionnaire were used to gather data. The researchers reported that, compared to the able bodied norm, respondents had significantly higher Personal Self, Moral-Ethical Self, and Social Self scores and significantly lower Physical Self scores. Perceived independence, provision of one's own transportation, assistance needed, and living arrangements were significantly related to self concept. Schulz and Decker (1985) and Decker and Schulz (1985) assessed a large number of subjects an average of 20 years after the injury using interview and three standardized psychological instruments. This study found that:

... persons who have high levels of social support, who are satisfied with their social contacts, and who feel they have high levels of perceived control report high levels of well being. Self-blame and the perceived avoidability of the cause of the disability correlated only moderately with the three measures of adjustment, suggesting that there are important differences between coping successfully immediately after a traumatic event has occurred and coping successfully many years later. (p. 1162)

The Qualitative Approach

These studies demonstrate a move to broaden the scope of long term adjustment research. There would seem to be a growing consensus about adjustment being a process which, of necessity, evolves over time. That length of time may have been underestimated by researchers to

date. What appears to be missing at this point are data linking short term adjustment strategies with data describing the successfully long term rehabilitated individual.

A qualitative research approach would facilitate exploration of the rehabilitation process over time, as conceptualized by individual's who have experienced it. The qualitative tradition evolved, in sociology and anthropology, from the explicit concerns for the cultural and social realities lived through by people (Munhall & Oiler 1986). Within this tradition the researcher's goals are to share in the meanings that the participants take for granted and then to depict the new understanding for others (Bogdan & Biklen, 1982). In contrast to quantitative approaches, qualitative methods do not require that there be a priori hypotheses. The purpose of these approaches is to uncover and generate concepts which help us to understand a given phenomenon or peoples' experience. From this point of view the real is not to be constructed or explained but described (Giorgi 1985). There is not one qualitative methodology but rather a variety of interpretive methods that all hold the primacy of the subjective experience (Munhall & Oiler, 1986). Marton (1981) describes these approaches as "second-order" perspectives. A "second-order" perspective can be characterized by a concern with people's views and experiences of the world in contrast to a "first-order" perspective which concentrates on observable behaviors, items or events.

This missing link was recognised by Oliver et al. (1988) who designed a study based on a conceptual framework of 'disability career' which denotes a complex relationship between the individual, social context, and the meanings made of the experience by the individuals.

The results of this extensive retrospective and descriptive study are derived from a combination of quantitative and qualitative data and are discussed in the book entitled Walking into Darkness: The Experience of Spinal Cord Injury. Drawing on the experiences of nearly 80 persons who had sustained their injury from 10 months to 14 years ago, the authors discuss the medical consequences of the injury, perceptions of the rehabilitation program, personal and family responses to the injury, living in the community, quality of life issues and financial problems. Conclusions are drawn which indicate the individual nature of the adjustment process, the length of time required in some cases, and have implications for the restructuring of existing rehabilitation programs and the creation of follow up programs for persons living in society. This is not the first study to use the idea of the 'disability career' as a means of ordering the presentation of the data (Safilios-Rothschild, 1970 and Blaxter, 1980). It is, however, the first comprehensive study which describes aspects of the adjustment process and individual responses in the words of the people with spinal cord injury themselves.

The Educational Approach

There have been a number of other studies, using a combination of quantitative and qualitative methodologies (Norris, Wharton, Noble & Stickland, 1982, Bleiberg & Merbitz, 1983, Kinash 1983, Waters, 1987, and Yarkony 1988), which have acknowledged rehabilitation within the formalized setting as primarily a learning process and have advocated a planned educational approach. Norris et al. (1982) developed the Spinal Injury Learning Series which combines learning and communications methods in order to identify the behavioral needs of patients with

traumatic spinal cord injuries, and to improve systematic training for improving cognitive and psychomotor proficiencies. Their extensive study demonstrated that use of this systematic approach resulted in faster acquisition and better retention of the information and procedures. Despite increased emphasis on learning theory in the rehabilitation process, no data are available to determine, or even suggest, the extent teaching and learning are reflected in rehabilitation practices.

Bleiberg and Merbitz (1983) attempted to address this problem in their study in which medical records of first admission patients were analyzed for the proportion of teaching/learning goals, plans and activities entered by professional disciplines on the rehabilitation team. Results indicated that 65 percent of the total chart entries reflected teaching/learning or attempts to accelerate or decelerate specific behaviors. The assumptions underlying these studies are that the priorities of learning needs are essentially determined by health professionals and that successful rehabilitation can be measured by the acquisition of certain behaviors and information. In contrast, Kinash (1982) and Waters (1987) considered learning needs as perceived by individuals with spinal cord injury in the rehabilitation setting. Their studies suggest that motivation is affected by discrepancies between learning needs identified by rehabilitation nurses and patients, and that optimal learning is achieved when teaching is organized according to the hierarchy of importance perceived by the learner.

These studies are based on the assumption that adjustment to a severe injury is a predominantly learning process and as such requires an educational rather than medical approach. The educational model

they advocate, however, is limited in scope as it continues to stress learning as the process of facilitating change in behavior or the acquisition, organization, retention and retrieval of knowledge. This traditional approach to the learning process allows little attention to be paid to the self-definitions of the experience, for example, "personal evolution," "assimilation" or "transformation" which have been recorded by Phillips (1985, p. 54) from oral narratives. These studies begin to acknowledge that how individuals with spinal cord injury perceive their learning needs in the rehabilitation setting may have profound effects on their motivation to learn and practice behaviors necessary for living with their disability in their own environment. The findings of these studies have been used to support the trend in rehabilitation settings toward a more systematic application of the educational model, learning theory and technology, by rehabilitation professionals. These studies, however, despite the emphasis on learning also unwittingly subscribe to the idea that treatment - the dispensing of units of care (Trieschmann, 1988, p. 37) - in this case the teaching of prerequisite behaviors, will lead to the improved ability of the person to manage life outside the hospital setting.

In summary, a major portion of the psychosocial research presented in this chapter has been directed at determining factors, of particular interest to the researchers, which contribute to adjustment of individuals to the disability resulting from spinal cord injury, and which predict who will cope and who will not. The methodology used has been predominantly quantitative and based on stages of adjustment theories. The terms adjustment, adaptation and coping have been indiscriminately used, often synonymously, as the goals of rehabilitation programs.

Outcome measures and evaluation methods of successful rehabilitation have been largely determined by health professionals. A growing interest in the individuals' perceptions of disability, and self-definition of successful adjustment, was identified in the literature. In response to this new focus, which supports the purpose of this study, qualitative research methods are being employed. The need to expand the focus of rehabilitation research, beyond the formalized rehabilitation program, to include the individual conceptions of the disability and the strategies used to integrate it into their social and environmental contexts, has been recognized. If assimilating disability into an individuals' life is viewed as a complex ongoing learning process, as some authors suggest, then studies of alternative methods of providing rehabilitation based on an appropriate educational model would be useful.

Chapter Three: RESEARCH METHODOLOGY

The purpose of this chapter is to discuss the methodological background of this research, and to describe the design of this study, the research process, data collection and analysis. I approached the study with a broad interest in understanding how individuals conceptualize the experience of traumatic spinal cord injury over time, rather than with specific questions to answer or hypotheses to test. This is in accordance with the literature which suggests that the purpose of qualitative research is not the formulation of new theories, but rather to provide new material or concepts which may act as the germ of an emerging theory and focus further data collection (Hammersley & Atkinson, 1983). The emphasis is on an attempt to understand the experience from the individual's own frame of reference. Strategies were employed in conducting this study which can be described as qualitative and interpretive.

Research Method

Qualitative research is used as an umbrella term referring to a number of different research approaches. It is frequently described, and justified, by contrasting it with the more established and accepted quantitative research or 'positivist' approach. Although a certain amount of comparison is unavoidable, I have attempted to describe the characteristics of qualitative research as they pertain to this study, rather than define it in relation to a quantitative approach. Bogdan and Biklen (1982) describe the characteristics of qualitative research as "soft", that is, "rich in description of people, places and conversations and research questions formulated to investigate in all their complexity

and in context" (p. 2). This research perspective can be clearly differentiated from quantitative research which concentrates on data collection and analysis which will support a pre-defined research question or hypothesis. The quantitative approach is concerned with external causes and measurable behaviors. Rehabilitation research, influenced by the medical model, has been dominated to date by this methodological approach. There has been a recent shift in viewpoint, as outlined in Chapter One (Dohrenwend & Dohrenwend, 1974, Oliver et al., 1988, and Treischmann 1988) to an examination of individual reactions to a particular life crisis or negative event such as spinal cord injury. This new focus of attention in rehabilitation lends itself to exploration from a qualitative perspective.

There are numerous qualitative approaches which, although they share certain characteristics, are viewed and evaluated by a number of different criteria. The qualitative research model arose from a disillusionment with the quantitative model which did not adequately inform researchers about the complexity of human behavior and social interaction (Jensen, 1989). From this disillusionment evolved the argument that the methods of social sciences should take a phenomenological or hermeneutical approach. The term "hermeneutical" is derived from the Greek word for interpretation. A dominant philosophy underlying qualitative approaches is that of phenomenology. From this position human beings are viewed as self-interpretative and that meaning, from the individual's perspective, has an essential place in the characterization of human behavior (Jensen, 1989).

The methodology used in this study is essentially qualitative and interpretive and draws from several schools of thought, described

briefly below, which have phenomenology as their underlying philosophy. Naturalistic inquiry developed as a direct rebuttal of the scientific approach or 'positivism'. Naturalism portrays research as a process of exploration in the 'natural' setting (Hammersley & Atkinson, 1983) in contrast to 'positivism' with its emphasis on 'artificial', controllable experimental conditions, and hypothesis testing. The focus of naturalistic inquiry is on the researcher assuming a totally non-directive role, manipulation of outcomes is avoided and multiple outcomes are allowed (Jensen, 1989). Hammersley and Atkinson (1983) suggest that, this approach, by not taking into account the reflexive character of social research, and by failing to acknowledge that the researcher is part of the world being studied, sets itself apart from the 'real' world in a contrasting, but equally inadequate, manner to the quantitative approach.

Phenomenology is an approach that concentrates on the subject's experience in the complexity of its context (Munhall & Oiler, 1986). Schutz's (1967) theory developed the idea of the role of consciousness in giving meanings to phenomenon, and the importance of common-sense interpretations of reality. "Meaning is a certain way of directing one's gaze at an item of one's experience" (Schutz, 1967, p. 42). Meaning is assimilated or understood through reflection. Donovan (1986) in her discussion of Schutz's contribution to phenomenology suggests that "behavior has meaning because it is an experience that has occurred and has been looked at reflectively. The meaning does not, therefore, lie in the experience, because experiences can only be meaningful if they are grasped reflectively" (p. 75). Phenomenology aims to describe experience rather than interpret, categorize, explain or

define it (Munhall & Oiler, 1986). Schutz (1967), in developing an phenomenological methodology, stressed the importance of the researcher role. According to Schutz (1967) the researcher is required to become immersed into the world of the subject without preconceived ideas or theories, so that a full understanding can be gained of what the life of the subject is like without relying on personal common-sense. The ideal of the 'neutral' researcher, or that "phenomenological inquiry begins with silence" (Psathas cited in Bogdan & Biklen, 1982, p. 31) presents methodological difficulties which have, according to Donovan (1986), "blunted the phenomenological critique" (p. 78).

Ethnomethodology, an offshoot from the phenomenological critique, does not refer to the methods that researchers employ to collect their data but to the subject matter to investigate (Bogdan & Biklen, 1982). Researchers using this approach try to understand how people go about seeing, explaining, and describing order in the world in which in they live. Like the phenomenologists, they are interested in the ways in which a sense, or meaningfulness, is established during the process of everyday interactions, and in particular, in exposing the underlying patterns of social interaction.

A sub-group of this approach is based on the development of the theory of symbolic interactionism. Basic to this theory is that human experience is mediated by interpretation, through which the individual constructs meaning which is always subject to negotiation (Bogdan & Biklen, 1982). From this theoretical perspective people in given situations often develop common definitions since they interact and share experiences, problems and background. These definitions are analyzed through the meanings and uses of language. The nature of

'symbols' is crucial and a symbol is taken to be a stimulus with a learned meaning (Donovan, 1986). Exploration of the shared characteristics of symbols within a culture, Donovan (1986) suggested, would enable people to predict other's behaviour.

Ethnography is part of the tradition of 'naturalism' (Hammersley & Atkinson, 1983) and is perhaps the most common term used when talking about qualitative research. It draws upon parts of symbolic interactionism, phenomenology, hermeneutics, and ethnomethodology. It was first used as a systematic research approach by anthropologists to study cultures. True ethnographies are analytic descriptions or reconstructions of intact cultural scenes and groups (Jensen, 1989). "The ethnographer's goals are to share in the meanings that the cultural participants take for granted, and then to depict the new understanding for the reader and for outsiders" (Bogdan & Biklen, 1982, p. 37). Initially the ethnographer begins as an 'outsider' in terms of both social acceptance and understanding of the culture and the emphasis is on the 'expert' informant or informants as being central to the research process. During the course of the study, however, the researcher begins to acquire acceptance and understanding, that is, possesses an 'insider's' view (Bogdan & Biklen, 1982). Inherent in the ethnographic approach is the acceptance that biases in social interaction exist and that the effects of the researcher's personal characteristics become an integral and beneficial part of the research (Donovan, 1986). Ethnographic research is characterized by a natural history of process, it does not occur, like scientific research, in linear lines but is shaped by the data, the researcher and the setting (Hammersley & Atkinson, 1983).

Despite a variety of approaches within the qualitative tradition, a number of shared characteristics can be identified. In conducting this study I have been guided and influenced by these general characteristics, which can be briefly described in the following manner.

The researcher is concerned with collecting data in the natural setting. The focus is on understanding the individual's or 'insider's' perspective; the way they make meaning or sense of their lives. In this way qualitative research illuminates the inner dynamics of situations - dynamics that are often invisible to the 'outsider' (Bogdan & Biklen, 1982). The researcher is the key instrument. The researcher's understanding, theoretical knowledge and insights are brought to bear on data collection and analysis. As a result identifying and stating the sources of bias and subjectivity in the researcher's own make-up is critical to the quality of the work.

Qualitative research is both descriptive and interpretive. In collecting descriptive data, in the form of taped interviews, field notes, videotapes, photographs, analytic memos, and personal documents, close attention is paid to the details of the situation. The written results of the research contain quotations from the data to illustrate and substantiate the presentation (Bogdan & Biklen, 1982). Interpretation is critical to the research process. Narrative description can be done in both qualitative and quantitative work, but it is the interpretation that makes the research meaningful (Jensen, 1989). The narrative data amassed is not reduced to numerical symbols but analyzed "with all its richness as closely as possible to the form in which it was recorded or transcribed" (Bogdan & Biklen, 1982).

Qualitative research is a process which is both systematic and flexible. The researcher enters the field with conceptual ideas which are derived from the researcher's own experience, a review of the literature and, in some instances, preliminary observations (Jensen, 1989). The emphasis is on the process rather than simply on outcomes or products. During the early stages of data collection the aim is to turn the conceptual ideas into a conceptual framework which provides the context for the research questions. As the researcher proceeds new insights and information are acquired which may result in a change of the research question or the issues being identified with more clarity (Hammersley & Atkinson, 1983). The goal of qualitative research is not the verification of a set, predetermined hypotheses but rather the generation of concepts that emerge from the data.

Collection of the data and the analysis of the data proceed simultaneously rather than following each other in a linear fashion. In this way, particularly in the initial stages, analysis of the data may enable the researcher to refine some aspect of the research (Jensen, 1989). The data collected is reduced by a number of analytic processes by which eventually patterns or themes are discerned. The process of data analysis is likened to a 'funnel' by some authors (Hammersley & Atkinson, 1983, and Bogdan & Biklen, 1982), being progressively focused over its course.

The research problem identified in this study developed as a result of the researchers' experience and from a review of the literature. The methodology of this research is derived from a number of qualitative and interpretive approaches and seeks to exemplify

several of the general characteristics of qualitative research described above.

Research Process

Methodological Decisions

Quantitative researchers speak of the design of a study as the product of the planning stage of research. The research process proceeds along a structured course of implementation of the design, systematic data collection, analysis and documentation of results. The qualitative design described for this study takes the same course but is less segmented and design decisions continued to be made throughout the study. The strength of this approach lies in the assumption that the participant perspective is central to understanding human behavior, and that the research is structured by the study process itself rather than preconceived ideas or a precise research design. The analysis of data is not a distinct stage of the research according to Hammersley and Atkinson (1983), but rather it feeds into the research design allowing a degree of reflexivity which is unique to qualitative research. The researchers' previous notions or 'foreshadowed problems' are seen as valuable tools - in this study represented by a knowledge of theory and current rehabilitation practice - which can be brought to the research by an informed researcher (Hammersley & Atkinson, 1983). This concept is clearly distinguished from the notion of "preconceived ideas" which can serve to impose an inflexibility on the research process and undermine the interpretive nature of the data collection and analysis.

In the course of conducting this research project I made a number of methodological decisions in response to the initial data

collection. My previous notions or 'foreshadowed problems' had lead me to anticipate that clearly defined differences in conceptions of disability would emerge from the data. Based on these expectations I had initially chosen to focus on a phenomenographic approach to the design of this study as the most effective method of exemplifying those differences. This decision impacted primarily on the data analysis and interpretation rather than on the study design and data collection.

Phenomenography is considered a 'research specialization' (Marton, 1988), which shares the characteristics of qualitative research described above, but is distinguished by certain criteria. The decision to use this approach was based primarily on the unique focus of phenomenography; its search for the variations in peoples' understanding of a phenomenon. This focus contrasts with other qualitative approaches which "seek for the essence or invariant meanings which people share about a phenomenon" (Stalker, 1988). This methodological decision had been influenced by my reading of the literature on the stages of psychological adjustment which tended to categorize the individual process into stages of adjustment to the injury. This categorization has been shown to be based on a consistent over estimation, on the part of rehabilitation staff, of the degree of psychological stress felt by patients. Such categorizations demonstrate an inability to recognize individual differences in reaction to a catastrophic injury, and a number of other contextual factors like family background, socio-economic group and age. My experience refuted this tendency to express the experience of spinal cord injury in terms of commonality and influenced me to choose an approach which focused on differences in experiential perceptions. During the first stage in the

process of data analysis, when I was reading the data in order to gain thorough familiarity with it, a number of consistent concepts began to emerge which suggested commonality rather than different ways of experiencing the phenomenon of spinal cord injury. This process, resulting in a decision to change from a phenomenographical approach to a more general qualitative approach, demonstrates the flexible, dynamic nature of the qualitative research process and is supported by descriptions in the literature (Guba & Lincoln 1981, Bogdan & Biklen, 1982, Hammersley & Atkinson, 1983, and Jensen, 1989).

The data collection method chosen was indepth semi-structured interviews. Through these interviews I hoped to identify the meanings attributed to the experience of spinal cord injury by each individual. The initial interview questions were based on Trieschman's expanded definition of rehabilitation. It became apparent to me, however, early in the research process while examining the data from the initial pilot studies, that the subjects had redefined the direction of the interview in response to my use of the terminology 'rehabilitation' and 'process'. The term rehabilitation was uniformly and consistently associated by the subjects with the institutionalized setting, and the physical recovery from the acute consequences of the injury that occurred there. Their interpretation of rehabilitation focused on the learning of new physical skills and behaviors which would allow them to sustain themselves in health and a degree of independence, and was consistent with that of the traditional medical model which had dominated practice so long.

It was not my intention to explore the experiences of the subjects during hospitalization in either the acute spinal cord injury unit or the rehabilitation centre in this study. The subjects involved in the pilot

studies expressed an appreciation for the support and information provided by individual members of the health care team, but in general voiced concern about the inadequacy and irrelevance of the information particularly in the areas of community services, financial, education and employment resources. The health professionals were seen as having a stereotyped view of the person with a disability and an inflexible approach to needs identified by those individuals. These views reflected an undercurrent of opinion noted in all the interviews despite the changing focus of the questions in subsequent interviews. None of the subjects interviewed had returned to the rehabilitation centre for follow up treatment since their initial discharge. As far as the subjects were concerned 'rehabilitation', that is, service provision appeared to end at the time of discharge and the subjects felt that they were left to fend for themselves. Whilst this study did not specifically set out to examine the provision of rehabilitation services, and how this provision is experienced by persons with spinal cord injury, these responses reflect the perception of rehabilitation held by these individuals.

In the context of this study, these interview results served to illustrate to me the constraint of language, and the barrier of communication existing between persons with a spinal cord injury and health professionals who seek to define the experience they observe in others. As a result of these findings I decided to delete the use of the terms 'rehabilitation' and 'process' from the interview schedule. It became clear that the conceptual framework for this study was not the rehabilitation process. The study was refocused on the learning process associated with a significant life event. These findings further exemplify the viewpoint that the individuals themselves must define the

experience and guide resource persons, who in turn acknowledge the individuals' expertise, and who are willing to be guided by their definitions.

The Researcher's Role

Researchers using a qualitative approach attempt to understand the meaning people construct around events or particular situations which impact on their daily lives (Bogdan & Biklen, 1982). Using this approach researchers orient themselves towards peoples' ideas or 'point of view' about the world (or their experience of it) and make their own statements about those ideas. It has been recognized that a 'point of view' is actually a research construct and may not represent the way the subjects think of themselves (Bogdan & Biklen, 1982). The goal of qualitative research is to intrude on the subject's 'point of view' as little as possible whilst recognising that it is, in reality, impossible to eliminate the effects of the researcher. The role of the researcher is seen as an active participant in the research process, and rigorous efforts are made to integrate and understand the effects of the researcher.

The extensive background knowledge and personal experience held by the researcher permits the recognition of complex situational variations and is considered an important advantage in interpretative analysis (Aguilar cited by Dyck, 1988). It is suggested, however, that the researcher should avoid direct involvement or feeling 'at home'. If and when all sense of being a 'stranger' is lost the researcher, functioning as research tool or instrument, may be unable to preserve the essential critical and analytical perspective (Hammersley & Atkinson 1983, and Bogdan & Biklen 1982). Glaser and Strauss (1967)

describe the researcher as "a highly sensitized and systematic agent" (p. 252) who may gain insights at any moment in the research process. Such insights may be gleaned from experiences prior to, or outside of, the actual research. The researcher, it is suggested by Bogdan and Biklen (1982), should try to interact with the subjects in a natural, unobtrusive and non-threatening way. A direct and personal egalitarian relationship with the subjects which engenders empathy and trust is seen as an essential component of qualitative research. The subject-researcher relationship needs to be thoroughly explored in order to accurately assess the information provided by the informant.

The terms 'insider' and 'outsider' are used to describe the researcher's presence in the research situation (Bogdan & Biklen, 1982 and Hammersley & Atkinson, 1983). Dyck (1988) defines "insider research [as the] study of one's own society, with the researcher participating as a member of the group being studied" (p. 103). The advantages of the insider perspective revolve around the true sense of understanding the informants' perspective. Understanding is in actuality a phenomenon of "shared meaning" (Bogdan & Biklen, 1982, p. 36). In contrast the 'outsider' comes to the research setting with no more than an academic understanding of the situation to be studied. My perspective, as researcher, in this study falls somewhere between that of 'insider' and 'outsider'. My own knowledge and understanding about spinal cord injury and its consequences, gained through close contact with those who have experienced it, permit the adoption of a relatively 'insider's view'. However, not having experienced a spinal cord injury presents major gaps in my understanding and so, in that

respect, I began 'outside'. Through an effective research process it is hoped that these gaps will become relatively narrower.

These insights and their connections with previous experience and knowledge are recorded in the form of fieldnotes; the written account of what the researcher hears, sees, experiences, and thinks in the course of collecting and reflecting on the data in a qualitative study (Bogdan & Biklen, 1982). In the course of this study I used two forms of fieldnotes (1) as a supplement to conducting taped interviews and (2) as 'analytic memos' (Hammersley & Atkinson, 1983). The former assisted me in capturing the meaning and context of the interviews and reflected my personal account of the course of the interview. Examining these notes in retrospect enabled me to reflect on technique and decisions made during the interview, clarifies insights and allows me to be self-reflective.

The methodical development of 'analytic memos' enables the researcher to trace the way 'reflections' have shaped the research design and emergence of themes. Themes or connections between data emerge during the research process and can be related in a continuous fashion to the literature being read. 'Analytic memos' provide a vehicle by which these reflections can be detailed and focused on analysis. Insights recorded in the form of analytic memos during the pilot studies enabled me to clarify the discrepancies which emerged between my definitions of 'rehabilitation' and 'process' and those of the two subjects involved. These insights were carefully reviewed and the interview questions refocused to make subsequent interviews less directive. Throughout the period of time when the interviews (ten in total) were being carried out, I read and re-read the transcripts, identified

emerging themes and continued to write analytic memos. In the course of analysis of the data I also continued to explore the rehabilitation and adult education literature in relation to the emerging concepts and themes.

Research Design

Selection of Subjects

In quantitative research random sampling insures that the characteristics of the subjects in the study appear in the same proportion they appear in the total population. Subjects are chosen by purposeful sampling in qualitative research. By this method particular subjects are included because they are believed to facilitate identification or expansion of a developing model or theory (Bogdan & Biklen, 1982). In this study there were a number of criteria which influenced the selection of the subjects: (1) All the subjects had sustained a traumatic spinal cord injury with resulting paraplegia or quadriplegia. This group was chosen for the study as they represent a young population, who are cognitively intact and who are required to make long term adjustment to the injury and its consequences (See Appendix A: Subject Profile). (2) All the subjects were between three and five years post-injury. This time frame was initially chosen to ensure that the subjects had progressed beyond the period of formal rehabilitation treatment in an institutional setting (average length of stay is 18 months for quadriplegics and 12 months for paraplegics). All the subjects, with the exception of one, who was 3 years post injury, were in their fifth year post injury. There was a concern that extending the period of time post injury beyond five years would detract from the

data obtained on the rehabilitation process as I initially defined it. The focus of the study shifted through the research process to investigating the experience of spinal cord injury as a significant change or life event. Oliver et al. (1988) suggest that the process of social adjustment can take up to 9 years. The time criterion chosen for this study may, viewed retrospectively, have been limited to five years unnecessarily. (3) None of the subjects had sustained a brain injury and all were capable of reflection upon the injury and its' complex consequences. (4) All the subjects considered themselves 'successfully rehabilitated' according to their own definition.

The problem of access to a network of potential subjects who considered themselves, and each other, 'successfully rehabilitated' was solved through the sponsorship offered to the researcher by a personal acquaintance, himself a quadriplegic, who was involved in organizing a peer support group. His endorsement and explanation of the research project to the group resulted in three persons volunteering to be involved. Further subjects were reached by a "snowball sampling technique" (Bogdan & Biklen 1982, p. 66) whereby the first subjects interviewed are asked to recommend others. "This technique, consisting of respondents contacting people they know who fulfill the criteria of research, is particularly useful when certain characteristics of respondents are sought" (Abrahamson cited by Dyck 1988, p.119). The interest in the project increased with each interview and further subjects were suggested by persons currently being interviewed. It was felt that this self-referral, and referral to others in their peer group, indicated an interest and desire to share their experiences.

The subjects who volunteered in this manner belonged to the same cohort group having met whilst inpatients at the rehabilitation centre. Consequently there was considerable variation in socio-economic and education backgrounds. The distribution of men and women (one woman and nine men) within the ten subjects involved in the study did not quite match the national statistic of 82 percent men. The age range was 21 - 39 years (average age 33 years) when interviewed and the causes of injury were motor vehicle accidents (9 persons) and diving (one person). The common factors shared by the subjects were that they were all injured in 1985/86 (with the exception of one), they had all shared the experience of traumatic spinal cord injury, and treatment at both the Acute Spinal Cord Injury Unit and the rehabilitation centre.

The initial contact with each subject was made by letter explaining the research study, the use of a tape recorder during the interview and the time commitment required. This letter was followed by a phone call two weeks later. One contact decided not to become involved in the study. At the beginning of the interview, in accordance with the requirements of the University of British Columbia Ethics Committee, each subject was asked to read and sign a consent form (See Appendix C). This form outlined in detail the purpose and focus of the study and gave an explanation of how the information gained from the interview would be used. The consent form addressed, to the satisfaction of all the subjects, any concerns they might have regarding use of the taped interviews and transcripts and confidentiality of the information provided.

In choosing an appropriate number of subjects for the study I had to give consideration to the time and resources available to me. The

subjects needed to be located within an hour's driving radius of Vancouver, be willing to spend 1 - 2 hours and share considerable personal information with me.

Data Collection

I chose semi-structured interviews as the dominant strategy for data collection in this study. Clearly structured, semi-structured and open-ended interviews are likely to provide different kinds of data and therefore will be useful at different stages of inquiry. The interview is seen, by Bogdan and Biklen (1982), as a purposeful conversation, usually between two people that is directed by one in order to get information. In this type of interview the researcher, having chosen the particular focus of the study, asks non-directive questions designed as triggers to encourage the subject to talk in that broad area. During the course of the interview the researcher can probe more deeply, picking up on specific topics and issues that the subject may initiate. Hammersley and Atkinson (1983) describe this as "reflexive interviewing" (p. 113) requiring the interviewer to be an active listener and participant in the interview process. The aim is to minimize, as far as possible, the influence of the researcher in order to facilitate the open expression of the subject's perspective.

The researcher is generally the only other person present in an interview and the confidentiality of the information is stressed. Under these circumstances, it is assumed that potentially the subjects will be free to divulge information and express opinions that they may not in the presence of others or in different circumstances. In this setting the

subject plays a stronger role in defining the content of the interview than in structured interviews.

Another factor which might contribute to the subjects' comfort in the interview is where the interviews are carried out. As Hammersley and Atkinson (1983) point out, "whose 'territory' is used can make a big difference to how the interview goes" (p. 125). Frequently allowing the subject to chose the location of the interview ensures greater comfort than if the interview were conducted in the researcher's office or a public place. For the researcher the interview is the focal activity at that particular time, this may not be true for the subject for whom it is just one isolated occurrence in the course of a day. This discrepancy must be taken into account when arranging the interviews leaving some flexibility for the arrangements to be altered should the subject chose.

The Interviews

All the subjects, with one exception, who chose to be interviewed in his office, were interviewed in their own homes at a date and time chosen by them. I gave careful thought to the length of time spent interviewing. Enough time was needed to facilitate a thorough exploration of the topic whilst remaining within the bounds of practicality for both the subject and myself. After the pilot studies I decided that 1 to 1 1/2 hours would be the optimum interview length. Permission was requested and granted by all the subjects allowing me to tape record the interview. The use of the tape recorder freed me from taking notes during the interview. I considered note taking to be both reminiscent, in a negative sense, of the institutional setting which both the subjects and I had experienced, and as interfering with the

interaction occurring during the interview. This interaction is described as 'sociable' by Strauss (cited by Hammersley & Atkinson 1970) that is, "the relations between interactants are neither impersonal or intimate. Sociable means interaction prolonged enough to permit more than a fleeting exchange but not so prolonged that close familiarity ensues...." (p. 30).

All the subjects were aware of my professional interest and knowledge as a physiotherapist specializing in rehabilitation, and eight of the subjects recognized me as having been practicing at the rehabilitation centre in 1985/86. In addition, I had been responsible for the physiotherapy treatment of three of the subjects during that time. The impact of these past connections, and in three cases, more direct involvement between myself and subjects, needed to be recognized and assimilated into the data collection and analysis.

During the interviews, I experienced these connections as valuable in both establishing rapport, and eliciting discussion. My detailed knowledge of spinal cord injury and its physical ramifications facilitated a level of trust from the onset of the interviews which would not have otherwise been possible. In one case, the discussion became particularly personal and emotionally charged and I made the decision that the information was beyond the scope of the study, and taping was curtailed temporarily. Usually in interviewing the interviewer must initially work to establish a tentative relationship with the subject and put the subject at ease. This stage of the interview process was minimized in this study because of the my past connections with eight of the subjects. The subjects were not self-conscious and were assured from the onset of my genuine interest in what they had to say.

This previously established relationship did, however, have its draw backs. I was associated, by the subjects, with the formal rehabilitation setting and as a consequence an expectation was created about the focus of my interest. It was found that the subjects anticipated concrete questions related to details of physical functioning and were initially confused, and even mildly resentful, when faced with the open-ended broad topic questions I used in the interviews. It was difficult, and often not feasible, for me to remain neutral during the interview and occasionally the interview resembled, for periods of time, a conversation between two acquaintances reminiscing, sharing jokes and catching up on news. After the two pilot studies had been conducted, and the transcripts examined, I used the consent form as a method of reinforcing my current area of interest. In subsequent interviews informal conversation and small talk were encouraged before the taping session began.

I felt, that in two cases, the subjects were particularly eager to represent their present experience in a favorable and positive light. This tendency is addressed by Hammersley and Atkinson (1983) who differentiate between the different interpretations of what is done "in public" and "in private." They suggest that, to the subject, the interviewer may not be seen as the most significant audience despite the assurances of confidentiality inherent in the consent form. The impression I noted, during these two interviews, may be attributed to the "other audience the actor is addressing, consciously or subconsciously (Ibid, p. 192). There was no method of exploring this impression more fully given my decision to conduct only one intensive interview with each subject. This information needed to be taken into

consideration in the analysis of the data in order to avoid making invalid inferences. It is, however, not the aim of the study to gather 'pure' data, but potential biasing of the information in this way may need to be recognised as a disadvantage of the one time interview and accounted for in the interpretation of the data.

On two occasions other people were present at the interview at the wish of the subjects, in one case a friend who interjected from time to time. This had the disadvantage of interrupting the flow of the account and was reflected in the transcript of the interview. On the other occasion the subject's wife was invited by the subject to contribute to the interview and her responses were recorded. One subject seemed ambivalent about the interview and was frequently distracted by the phone ringing, making a cup of coffee and talking with the home maker who arrived during the interview. It was felt that this interview was less effective in acquiring information for the study than the others. It is important, however, to bear in mind that information gained in this type of study is cumulative, each interview building and connecting with the other (Bogdan & Biklen, 1982), so it was decided to include in the study the data obtained in this interview.

It was my goal, before and throughout the interview, to regard the subject as an expert consultant. I felt that this goal was achieved and due to this, and the ease established between the subject and myself, the interviews were considered on the whole to be successfully conducted.

After each interview I listened to the tape and recorded, in the form of notes which were added to the transcripts, impressions, nonverbal cues noted during the interview, and any insights triggered

by the subjects' reflection on the topic. The tapes were transcribed verbatim within ten days of the interview. These transcripts formed the main 'data' for this study.

Pilot Studies

I started the study by conducting two pilot studies with volunteer subjects who met the criteria. Indepth interviews were conducted using a variety of trial questions related to the general topic of interest. In this way the proposed questions were checked to ensure that they related to the research question, were appropriate, clear, unambiguous and not leading. The pilot studies served to familiarize me with the qualitative process and alerted me to biases I held about the topic. They provided an opportunity to collect data, do an initial analysis and receive feedback from my advisor.

These interviews were both 2-3 hours long and the discussion was dominated by accounts of the hospitalization period, learning new physical skills and their physical functioning since discharge. The subjects were asked to read their interview transcripts and comment on the effectiveness of the questions. As a result of this feedback and the initial data analysis the discrepant definitions of 'rehabilitation' and 'process' held by me, as a health professional, and the subjects were identified. In subsequent interviews I decided to delete the terms "rehabilitation" and 'process' from the questions. The interview questions were revised (See Appendix B) to begin in a general way and attempted to elicit descriptions of the individual's experience of spinal cord injury since hospitalization. These questions served the purpose of opening up the discussion, the flow of which was maintained by probing

questions designed to clarify and encourage the subject to elaborate.

The pilot studies were invaluable in assisting me to more effectively focus the interview. Following these new question guidelines, subsequent interviews were shorter and less dominated by the physical ramifications of the injury. The pilot study subjects allowed me to practice the revised questions on a second occasion. These second interviews were transcribed and the data incorporated in the study. In this way, analysis of the data began early in the research process and included working with the pilot study subjects on refining the interview questions, becoming familiar with the interview transcripts in a general sense, formulating a range of concepts related to the growing data, and recording insights arising from the interviews and additional reading. Employing these methods provided me with an on-going opportunity to reflect on the research process, and aided the actual analysis of the 'main' data contained in the interview transcripts, which is discussed in the next section.

Data Analysis

Data analysis began with several thorough readings of the transcripts in their entirety in order to gain a sense of the context of the emerging conceptual issues, and of the totality of the data. Hammersley and Atkinson (1983) suggest that "at this stage the aim is to use the data to think with and one looks to see whether any interesting patterns can be identified" (p. 178). Some of these patterns had already been noted in the transcript notes and the analytic memos and could be developed into a number of thematic categories of description or conceptions for which criteria were established. Categories are the

primary method of organizing qualitative data. The data were then examined closely for words, phrases, sentences or paragraphs, that is quotes of the subjects' actual words, which represent these categories. The labelling of these 'quotes' is not well defined in the literature describing the analysis of qualitative data. For the purpose of this study these extractions from the transcripts or quotes will be described as units of meaning.

The data were organised by an ethnographic method described by Hammersley and Atkinson (1983) as physical sorting. I identified units of meaning and coded them by subject initial, response and page number. Separate lists of these coded units of meaning were made and copied, so that the original transcript remained intact. This list could then be cut up and individual units of meaning assigned physically to the relevant thematic category or categories, initially in file folders and later on flip chart paper mounted on a wall. This method had the advantage of arranging the data in readily available groupings, and the categories could be placed side by side and compared.

The categories of description and conceptions are in this way grounded in the data. They are both constructed by the researcher, and abstracted from the language used by the subjects in describing their experience. Construction of the categories is not merely a matter of description but of selection and interpretation (Hammersley and Atkinson, 1983). It was felt that this on-going analysis was enhanced by my familiarity with some of the aspects of spinal cord injury, and that it enabled me to draw from the data conceptual and substantive issues which might have been missed by a relative new comer to the field. The disadvantage of 'preconceived ideas' which might bias me, as

the researcher, towards a particular interpretation of the data was anticipated. To counteract this possibility a colleague, who possesses knowledge of qualitative research and physical disability, was on occasion asked to assign data abstracted from the transcripts to the established thematic categories. Discrepancies in assigning units of meaning, which arose between the colleague consultant and myself, caused me to reflect in depth on her interpretive decisions. By removing, in the final stage of analysis, the units of meaning from the context of each interview transcript, the connection of the data to individual subjects was severed and, in this way, were no longer of concern to me. The analysis was continued in the presentation of the data and the inferences drawn from them. The categories of description once derived were examined for connections and differences. The end result of analysis is the formulation of three conceptual themes which emerge from the subjects' learning experience following spinal cord injury. These themes are presented and discussed in the next chapter.

Chapter Four: PRESENTATION OF DATA

In this chapter, congruent with the purpose of the study, an analysis of the data, derived from in-depth interviews, related to the conceptualization of the experience of spinal cord injury, will be presented. The theoretical assumptions outlined in Chapters Two and Three will be used as a framework upon which discussion of the data will be based, and examples will be illustrated with quotations from the individuals with a spinal cord injury who participated in the interviews. Each individual's role as expert informant in this study is acknowledged. In the course of conducting this study it became clear to me that each individual I interviewed was engaged upon a unique and intensely personal learning process. By learning to assimilate disability into their lives these individuals not only transcended the disability but developed as adults in ways that they found different from pre-injury and frequently more satisfying: "I grew up," "I like myself way better now," "I really changed my whole attitude to life" and "I was going nowhere before and now look at me."

The subjects who participated in this study defined themselves as successfully rehabilitated, or at least, well on the way to becoming successfully rehabilitated. As discussed in Chapter Two the term 'rehabilitation' proved inadequate as a descriptor of the process experienced during the years post-injury. This inadequacy was drawn to my attention as a result of the comments and responses made by the subjects during the initial interviews. In this chapter the term 'rehabilitation' is used only in reference to the formalized provision of rehabilitation services by health professionals. In the context of self-

definition 'successfully adjusted,' or simply 'successful,' could be substituted for 'successful rehabilitated.' There is no standard criteria by which these individuals measured success. Their highly individual definitions of success are related more to "the quixotic interpersonal environment in which each must self-determine their social and personal goals" (Phillips, 1985, p. 48). Central to these self-definitions of success are the 'meanings' each individual attaches to the experience of disability resulting from spinal cord injury.

The ensuing presentation and description of these 'meanings' may appear to the reader as overly positive and biased towards the high achiever type of individual. This bias is an intentional part of the design of the study. In choosing subjects for this study I purposely encouraged those people who defined themselves, and in some instances were defined by their peers, as successfully rehabilitated (the phrase used at the beginning of the study). The emphasis was on self-definition and it was this criteria which the resultant pool of subjects shared. In all other respects these individuals presented different personal and lifestyle profiles.

This diversity can probably be best illustrated by providing brief profiles of two individuals, one whom in my opinion epitomized 'successful' and one who did not. Douglas, whose injury was sustained at the C5 level resulting in quadriplegia, at 26 years of age is adamantly independent of his family. He lives on his own in a cooperative apartment with his dog. An attendant, whom he hires and trains, assists him with hygiene and personal care in the mornings. Douglas has just completed a degree in history and will pursue his goal of becoming a history teacher by enrolling at university in September of 1991 to

commence an education degree. He leads an active life both socially, and as a computer resource for his peers and a cooperative housing management committee member.

Malcolm, whose injury also resulted in quadriplegia but at the C7 level, making him functionally more independent than Douglas, has resumed his pre-injury involvement in the entertainment world. He has reformed a group of musicians which he fronts as vocalist. Since his injury he has produced an album of his own songs and the group are currently engaged to play at a number of venues in the city. Malcolm has a long standing drug abuse problem which he acknowledges has more serious consequences now that he is disabled. These consequences were evident to the researcher during the interview. Malcolm looked unkempt, there was a pervasive odour of urine in the apartment and he mentioned persistent skin problems he was experiencing on his elbow and buttocks.

As the researcher, I became aware, early in the study, that my personal interpretation of successful rehabilitation did not, in some instances, correspond with those of the individuals involved. In reviewing my own reactions to these two individuals, and to the others I interviewed, I became aware of the expectations and prejudices which shaped my own definition of success. It is hard to discard the emphasis placed by the rehabilitation system on the physical aspects of disability. It became clear to me that my positive reaction to Douglas was the result of his personable appearance, aura of responsibility and his pursuance of goals I judged to be worthwhile. Malcolm, on the other hand, neglected these attributes that I valued and instead pursued his life basically in the same way he had done before his injury. His intense

interest in writing and performing music continued to dominate his life, to occupy the forefront of his life whereas his physical well being, that is, his disability, was relegated to the background. He clearly defined success by different criteria than I did, but in the final analysis the only choices and definitions of any significance were those by which he guided his life.

The meanings attributed, either consciously or subconsciously, by the subject to the injury, which emerged from the analysis of the data have been organized in terms of three themes: Rediscovering self, redefining the disability and establishing a new identity. These themes reflect the ongoing process of constructing a sense of self which each individual is embarked upon. This process can be likened to the natural history of development of a person with a disability. As such, the themes as they were identified from the interview transcripts and data analysis, have a chronological pattern which has directed the presentation in this chapter. This presentation, however, is not intended to resemble the stage models of adjustment or to suggest an expectation of logical movement between themes. There is no definitive ending of one and beginning of another but rather an interweaving of different elements of the themes unique to each individual's experience.

Rediscovering Self

The subjects in this study had, prior to the injury, to a lesser or greater degree, a well established sense of inner and outer self. The notion of 'self' is conceived to be the conscious image of the core of one's being which is held by an individual, and which is seen as distinct from all others. It is the subjective sense of one's own continuity and

character, acquired through experience. It is from the framework of this internal 'self' that an individual interprets the external world and interacts with it. The inner or private experience of self involves the perception of intimacy in significant relationships, the setting and achievement of personal goals and an overall sense of control over one's life. Mead (cited in Miller, 1982) stresses the continuity component of the definition of 'self.' 'Self' is seen as not merely rooted in immediate experience but continuous in memory with the past but also in anticipation with the future. "Self stands for the individual as he will conduct the discussion tomorrow" (Miller, 1982, p. 186). For Mead, the self cannot be separated from action which involves a relationship between the mind, the body and the physical environment as well as the social environment.

Post-injury the inner self, that is, mind, character, emotions, conscience and aspirations which constitute their private experience remain the same as before the injury, firmly rooted in the able-bodied normality. As a result of spinal cord injury these individuals were thrown into a radically altered experience of the functioning, appearance and image of their own body. The disability and overall sense of loss are initially symbolized by the physical changes or the external experience of the disability. These are separate from the internal concept of 'self' which remains essentially unchanged. What develops, however, is an inner conflict which can be best described as an experiential split.

The theme described as rediscovering self is concerned with those components of the post-injury experience which inhibit and facilitate a reintegration of the internal and external selves. The inhibiting factors

include the sudden loss of control over physical functioning and capabilities, alienation from the 'real world,' the restrictive environment and instructional limitations of the rehabilitation facilities, and the attitudes of the health professionals providing education and care. The individual embarks upon a complex learning process which is facilitated by the continuity of their sense of 'self' and which facilitates the resolution of this experiential split. This process is associated with a gradual build-up of a new framework of experience upon which the individual can base new learning and make decisions for the future. These individuals bring to the situation personal resources accrued from their pre-injury experience.

Listening to the accounts of people who have experienced the dramatic and sudden change to their lives caused by traumatic spinal cord injury, one gets a sense of the importance of understanding the nature of the event which transformed them. The subjects all spoke cogently of the ongoing difficulties of coming to terms with their disability, and retained clear memories of their initial responses to injury. These initial responses to the injury varied a great deal, but all conveyed a sense of loss of 'self,' and overwhelming feelings of shock and disorientation.

In attempting to verbalize the enormity of the changes in his life Randy said:

It's like being shell shocked, your whole life changes. I was in the process of being married in November, which was only a couple of months away. I had my own beautiful home, you know, well established, my own business. I mean all that was lost, absolutely lost.

The reality he describes changed virtually overnight to one of physical dependence, the prospect of being institutionalized in a long term care facility, and the end of his relationship. During his acute and early rehabilitation treatment his ex-fiancee claimed, and negotiated through a lawyer, a major share of his holdings including his house and business. He never returned to his house which was sold while he was in the rehabilitation facility. Ian, injured at the T8 level and comparatively stable in terms of returning to relationship, house and marriage, at least in the opinion of 'outsiders,' was so overwhelmed by the changes he was facing that he admits to contemplating death as a preferred option:

If someone had given me a choice between being dead or alive two days after my accident I would have said "kill me, I don't want to live like this." But time has a way of changing your attitude, the way you think about things.

Brian, whose C7 injury was caused by a diving accident while on holiday in the Caribbean, claimed that:

I think I started rethinking right from the accident. Just lying there on the beach, thinking about the things I couldn't do, started me thinking about a friend of mine who is a quadriplegic. Seeing what he does I sort of knew straight away what was in store. Life doesn't stop, so I focused on the things I could do right from the start and it's just got better with time.

For some people the initial sense of disorientation and shock was short-lived, whereas for others it took much longer to come to grips with the implications of the injury. Deeply embedded in this, and the other accounts, is the significant impact that the onset of physical disability had on self-concept.

The term self-concept can be interpreted as a bridge between the 'self' and the physical and social environment. It is a generalized vision, conceived by an individual, as an amalgam of abilities, talents, defects and overall independent functioning, and by which the 'self' is revealed to others. One of the primary mechanisms by which one is revealed to others is through physical appearance and interaction. Consequently, self-concept is closely related to body image which encompasses the person's perception of their physique, features and aesthetic appearance. The primary imperative after the injury appears to be to restore self-concept by gaining a degree of control over the external 'self' which is the most radically changed, and which demands immediate attention. The instruction provided in the rehabilitation setting, while limited in scope, does address the physical changes and facilitates the development of a framework of knowledge and experience from which evolves a renewed sense of self-responsibility and purpose.

The Experiential Split "It's the same old me but..."

Sudden trauma results in radical and irrevocable changes in physical functioning and appearance. These changes are exacerbated by equipment, such as, wheelchair, braces, catheters and urine collecting devices. This equipment, frequently evident to all, serves to further alienate the individual already coping with the stigma of being disabled. Some of the equipment is associated with a loss of control and normal functioning of the body. Malcolm said:

Everyone sees the wheelchair and they think because it's the most visible thing that that's the hardest thing to deal with. Not being able to walk is not so bad but not

being able to tell when you're going to the bathroom is even worse. It is so humiliating when you have a bowel movement in company, or your urine drainage doesn't work and everything gets wet.

Control over one's life, at this stage, is virtually non-existent and individuals' are dependent for survival on others. Control and independence are characteristics commonly cited to differentiate adults from children. Loss of these characteristics, however temporarily, may represent for the individual and those providing care, a regression to childhood. The onset of spinal cord injury immediately alters an individuals' sense of self-esteem. A whole series of familiar definitions of 'self' are changed: "I am a athlete," "I am a capable father," "I walk," "I ride a bike competitively," and "I waterski." All of these "I am" definitions are related to physical appearance and capabilities or the external 'self.'

Self-esteem is one's good opinion of one's dignity or worth. It is an indication of the degree to which one can regard oneself as commanding respect, or being admirable, important or useful. The concept of self-esteem is to a greater extent derived from the opinions of others, through belonging to the majority group, that is the able-bodied population, and accepting society's norms as criteria for governing behavior. Self-esteem constitutes a relationship of 'self' with society and, as such, can be described as the public or external experience. Randy, who sustained a high level injury, was clear about the difficulty he has had assimilating his changed public image. His feelings about his body during the first two years are encapsulated in this statement:

It was devastating, for the longest time I wouldn't look in the mirror. All I could see was that it was shrinking, going through all these wierd changes. I was losing the way I'd

looked in front of my eyes, didn't know myself anymore.
Like it couldn't be me!

A resulting consciousness of an experiential split was expressed in the language of some of the subjects' accounts. Ian remembers discussing this with his wife:

Ron Kovak the guy who wrote Fourth of July described it as losing his body, not his mind as he knew it, but losing his body as he knew it. My wife asked me at the time if that was how I felt and I said "Yes, it feels as if your body is someone else's." Your mind's the same and you think of yourself in the same way.

It seemed to me that the paradoxical quality of these descriptions of this phase of experience is related to the individuals' perception of the continuity of the inner sense of self which is sustained in spite of the radical external changes:

I've definitely changed since my injury. I'm still pretty much the same person I was before.

It appeared that the paradox was so deeply ingrained into each individual's efforts to cope with being disabled in society that, during the interviews, their verbal contradictions went unnoticed. For example, Douglas said when I asked him about his social interactions:

It's the same old me. There has been nothing that's changed except where I'm sitting.

and then a moment or two later:

It feels as if I've lived four different lives since my accident, I've been through so many changes.

For Randy, the familiar 'inner' self continues to be overwhelmed by the external experience of the injury:

See, I really have a hard time going out in public in a wheelchair. It's not so bad now. It's not really that people are staring at you. It's yourself and you've got to accept yourself as you look now. You've got to think you're O.K. before you can go out and feel O.K. I'm almost there but not consistently. I'll have to get used to it in the end, I sure can't walk away from it can I?

Initially Randy coped with this loss of self-esteem by simply not going outside the rehabilitation centre. This separation of inner self from his body extended to situations where he received care from health personnel. At these times his strategy was one of "simply turning off." As he explains:

I'd go somewhere else in my mind. Go to a happy place. If they had a problem it would snap me back to reality. Eventually I began to realise that it was still my body and I had better attend to it a bit more.

The strategies he initially employed were not reality based, rather they are focused on escaping the reality, and resulted in the non-integration of the private and public selves and a severe loss of self-concept. This may be an essential mechanism for coping with the enormity of the injury in the early stages but from this perspective the disability is defined as out of control. As Randy said, quoting a line from a David Bowie song he knew I would appreciate, "eventually you've just got to turn and face the changes."

Integral to the learning process is an assimilation of the reality and the implications of the new body image and altered physiological function. The subjects stressed the need to "establish a language with your body," 'to tune into it,' and that this ability resulted from experience. This acknowledgement of the disability, and the implications it has on lifestyle was considered, in most cases, to take at

least 2 - 3 years. For Randy, who uses an electric wheelchair, coming to grips with the equipment and the associated image change continues to be a source of stress:

I find one of the hardest things to deal with is relationships with women. I mean it's hard to get beyond the way I look. It's hard to imagine the intimate part - being a quad lying in bed with someone - it's pretty hard to deal with. I mean sometimes you get spasms and they can be pretty embarrassing.

In contrast several people expressed a degree of pride in the control they felt with regards to their body:

I've become so much more aware of my body and seem to have more control of it than I had ever expected.

The body is an amazing thing, it will tell you essential things which make life so much easier than at first, when there seems to be no communication between it and the mind.

Initially the impact of this experiential split, and the attempts to reconcile it, direct the focus of each individual's efforts to adjust to the radical changes that have occurred as a result of the injury. This focus is reinforced by the rehabilitation program in which they are engaged during a minimum of one year post-injury.

Regaining Control "It's like doing hard time"

Self-concept, then, is initially dominated by the survival issues and physical changes which are addressed in the sheltered environments of the hospital and rehabilitation settings. The impact of the perceived experiential split renders the individual vulnerable to the opinions and influence of health professionals. Rehabilitation was associated, by the subjects, with dependence on others and loss of

personal control and the ability to make informed decisions. This loss of control is compounded by lack of knowledge about the injury and its ramifications, fear of future capabilities or lack of them, and a severe loss of self esteem and confidence. As Ian put it:

The first couple of years are the worst, terrible, things don't go well. Everything becomes an incredible effort and physical challenge. Everything about your body has to be relearned, just like a child, only a thousand times more difficult, but at the same time you have to keep the rest of your life going somehow. I mean life doesn't stop conveniently while you get reorganized does it?

The contrast between the newly acquired post-injury dependence and lack of knowledge and experience, and the pretrauma conceptions of self as a capable adult with all the rights and responsibilities inherent in that role, is a dominant factor during the first two years post-injury. The pre-trauma conceptions of self do not apply: new conceptions have not yet emerged during the rehabilitation phase and on initially returning home. There is a sense of being arrested in time. The consensus of opinion about this period of time is summed up in these statements:

For the first two years you are in a bit of a deluded state, there's so much happening over which you have no control, so many things going on in your life all of them new, you get a bit mixed up.

I always had a purpose before my accident. I completely lost it after for about two years, it took along time to get it back. It's hard to see the purpose at first.

You've got to get your two years in, it's like doing hard time, like being in jail.

Brian's analogy of 'jail' is closer, I think, to the real experience of the 'patients' than rehabilitation personnel would like to believe. There is a sudden, severe reduction, on admission to the hospital setting, of all that characterizes these individuals as adults. These characteristics centre on the notion that an adult has developed a sense of control and autonomy over their bodies and lives. Like prisoners, they are stripped of the framework and trappings of their lives and reduced, particularly during the first year post-injury, to issues of survival. As Dirk said:

I couldn't believe it. I was so independent before my accident. The staff were very kind to me but they treated me like a 10 year old child. I brought in photographs of me before the injury but they didn't seem to connect, and looking at them just made me feel worse.

From the subjects' accounts the analogy of 'jail' would seem to have a dual source of origin. On one hand there is a sense of being trapped inside a physical shell over which one has no control or understanding, and on the other, they are dependent on the provision of rehabilitation programs. These programs seem to be dominated by an institutional bureaucracy which takes precedence over the particular needs of individual. As Douglas said:

The rehabilitation setting is beset by policies and procedures which don't allow for individual needs and differences.

Rehabilitation programs tend to be delivered in accordance with complex daily schedules. These schedules allow little or no flexibility for either the 'patient' or individual health professional. Within this type of organization the 'patient' becomes the passive recipient of instructions and guidelines from health professionals. As Malcolm commented:

I really have to dig into my memory to recall that time. I think I have deliberately blocked it out. I can remember the music projects I got involved in during that time, but I don't remember the pain, toilet, this and that done to me every night or every two days. Always wondering what was happening, going to happen next, or if I was going to void in public.

These programs focus on skill and behaviour mastery within the institutionalized setting and consequently alienate individuals from their personal and social context. Several of the subjects reiterated the thinking of Dirk who said:

On discharge it was difficult to cope and get back into a family lifestyle. You have to relearn to live with people again.

The instructional emphasis of the rehabilitation program focuses almost entirely on muscle strengthening, skill acquisition, for example, wheelchair to bed transfers and habit development, such as, bladder and bowel management routines. William recalls rehabilitation as:

Mostly physical stuff like stretching by the physiotherapist, strengthening and in occupational therapy learning how to help others transfer and dress me.

Accomplishments such as achieving sitting balance, wheelchair to toilet transfers, which are meaningless from a 'normal' person's perspective are "symbolized by rehabilitation staff as indicators of progress" (Cogswell, 1984 p. 162). Cogswell (1984) suggests that in the early stages after the injury, individuals with spinal cord injury accept these symbolic definitions, and derive self satisfaction from the mastery of steps which under other circumstances would be considered inconsequential. This emphasis in overcoming physiological and physical

disability reinforces the success-as-normalization perspective inherent in current rehabilitation programs.

Newly disabled individuals are particularly affected "by what may become for them an unending pursuit of form and function restoration" (Phillips, 1985 p. 57). If they do not succeed in defeating their disability, which given the neurological damage incurred by spinal cord damage is unlikely to be the reality, the message they end up with is one of failure. Those who continue to strive for the goal of social 'norm' and to some degree achieve that goal are viewed as a 'supercripples' and singled out as having exceptional courage. By implication this devalues other people with disability who are unable, or do not have the desire, to define their lives in terms of society's 'norm.' By acquiescing to the perspective of 'normalization' the individual's learning processes become blocked by the traditional and stereotyped definitions of success inherent in it.

Limitations Imposed by Others "They told me I couldn't"

The subjects, while appreciating the support and assistance provided by individual professionals within the rehabilitation setting, spoke of their struggle against attitudes, preconceived ideas and assumed knowledge. Frustration was expressed at the double message given by rehabilitation professionals, that is, you must learn to be independent as a person with disability but we will make all the decisions for you. In Randy's case, plans were made by the rehabilitation team for him to be discharged to a long term care facility which he considered to be totally unacceptable. Randy describes how he began to reassert his sense of self, "became more like the old me," in gaining some control of the situation:

"I did battle to stay, even involved my lawyer until they came up with some more creative options. I knew if I went there [the long term care facility] I would never get out.

Randy has lived, since discharge, in a group home with three other people, and he foresees that in the future he might be able to financially support his own apartment and attendant. Ian and Nairn were told that having their own baby was impossible. As Ian said:

They told me "No" to that and other things. No's really hard to take; if they'd said "maybe," I might have been able to accept it a little better but they just kept saying "No." I'd heard "No" to many times at that point.

They have since explored the medical options and advances and their daughter was born six months ago. Her birth seems to be symbolic to him:

All the things they told me I couldn't do, are all proved wrong now. Every time there's one more thing I can do that they told me was impossible in my life, I realize that being handicapped is a lesser problem than they lead me to believe.

All the people I talked with recognized, in hindsight, how influenced they were by the professionals' dominant attitude of the injury as 'tragedy,' with the resulting emphasis on the devastating aspects of the injury, and how this subtly undermined their own sense of competence and ability to make decisions in the new context of their lives.

Pervasive in these accounts of their experience is the anger directed towards the professionals' invocation of expected accomplishments related to level of injury. For those persons with higher levels of injury, that is less available physical function, these expectations resulted in limitations being imposed at an early stage.

Brian said:

People told me things at first which kinda blew me away,
like the physiotherapist who just baldly told me "you can't
do that at your level."

Randy, struggled to come to grips with a high level injury and to sustain
his sense of self in the face of the professionals' opinions:

They tell you that you can only do so much at your level,
and in your heart you think no way I can do more than
that, and so you try and keep a positive attitude in the face
of all that negative feedback.

For persons with lower levels of injury these expectations could affect
morale in an opposite sense:

I got mad during rehab when they would accuse me of not
trying. They used to say at your level you should be able
to... but I had so many other injuries. I rarely felt that I was
improving as I should, or doing enough, although I was pushing
myself as hard as I knew how at the time.

A serious overall curtailment of options would seem to occur
when professionals adhere to the stereotyped role for the disabled,
particularly when associated with level of injury or 'functional
outcomes'. Albrecht (1976) suggests this limited viewpoint offers "a
single 'appropriate' model of thinking and behaving for the disabled
person and precludes a whole range of 'inappropriate' options,
regardless of the individuals' abilities, talents and inclinations" (p. 41).
Through my experience as a physiotherapist in the rehabilitation setting
it became evident that those people with disabilities who are seen to
seek 'inappropriate' options, or do not conform to the status quo, are
frequently labelled as 'difficult', "demanding," 'non-compliant' or 'non-
accepting of their disability.'

There is nothing in the data to suggest that the subjects in this study challenged the system in this way while actually involved with it. The subjects appeared to have been faced with the dilemma of not knowing what they needed to know while in the rehabilitation setting. This dilemma reduces the power of the individual to direct their learning process and, it is likely that, during this phase the subjects were unable to overtly challenge the system except under isolated circumstances. However, in retrospect, after discharge from the facility these individuals began to question the expectations and 'norm' stereotypes adhered to by the health professionals providing rehabilitation service. The attitude and expectations of rehabilitation personnel can profoundly shape the self-image of a newly disabled person, at a time when the individual is vulnerable and in the process of questioning the identity changes resulting from spinal cord injury.

The instruction received in the rehabilitation setting was viewed by the subjects as providing essential information and the opportunity to practise important skills. It gave them the tools which allowed them to move onto the more challenging environment of their own social context. Whilst the pedagogic approach to instruction was questioned, and subjects considered that under some circumstances it undermined their self-confidence, the instruction they received was seen as essential to their process of adjustment. As Douglas, who sustained a C6 injury, described it:

If your physical rehab is no good, then your mental rehab is going to be a helluva lot longer because you're still dealing with your physical stuff. I think it's really important to have well-trained, dedicated people in that phase of your rehab.

I was really lucky in that respect. But then you leave the rehab and there suddenly seems to be a real gap, a total lack of information. I wasn't prepared for that at first.

For the subjects in this study, who were self-defined as successful, the rehabilitation setting provided an "initial grounding" but after discharge other instructional influences quickly took precedence. As Peter said:

I don't know if everything they did in the rehabilitation centre was actually the right way. I've found since that there are lots of different ways of doing the same thing. You have to improvise, try out different things at different times. I think having variety is good, don't get locked into the idea of there being only one right way, like they lead us to believe.

Trieschmann (1988) suggests that the rehabilitation environment is essentially a deprivational one, since the 'patient' does not have the opportunity to perform the majority of socially determined acts whose performance was at the heart of normal daily transactions before the injury. The subjects acknowledged that the time spent in the rehabilitation setting:

Gets you back on your feet again pretty well, in your chair
I guess, teaches you essential skills, gets you on the right
track in a functional sense.

However, in general, they felt that there were critical gaps between what was taught and what was required on discharge into the community. These opinions are reflected in Tricia's comment:

The things you learn in rehabilitation are sort of preparation, but the trouble is they don't always apply when you get into the home situation. In rehabilitation everything's done for you. Major difference between the things you learn yourself from experience and the things you learn in rehabilitation.

Douglas also said:

The real learning is when you get out of rehabilitation, when you get out and have to face reality, and deal with everything on your own.

These comments reinforced the impression, I had already developed, that rehabilitation education occurs in a social vacuum, isolated from the demands of everyday life, and that it effectively ends at the time of discharge from the institution. Inherent in the rehabilitation program are the expectations that on discharge individuals should be capable of assuming the mantle of adulthood, and of launching back into their old lives in a fully functioning fashion or 'as nearly normal' as possible. This is not the reality, nor does the educational approach to rehabilitation provision facilitate the attainment of these expectations. To the contrary, as the subjects have stated, the primary learning is seen as beginning on discharge from the rehabilitation program.

Acknowledging Self-Responsibility "It's my life"

Inherent in accepting the challenge of living with a disability is the dawning awareness, during the rehabilitation phase, of the increased need for self-responsibility. This awareness crystallizes, upon discharge from the rehabilitation setting, when the individual is confronted the wider context of society. The reality of this context encompasses radical changes in employment and status, the need to re-establish personal and social relationships, and overcome environmental obstacles.

Many people return to a home environment which is alien to them, they are inexperienced in troubleshooting the physiological

changes, and are without resources in the form of professional follow up or role models. Dirk described how difficult this transition can be:

We [his wife and two sons] moved to Merritt after I was discharged. I had a house that was totally renovated for a wheelchair. We lived there for two years, but due to complications with being a new quadriplegic, and learning all those things we parted company. I tried to stay in the house but there wasn't any sort of help for people in chairs, so I had to move back to Vancouver into a group home which was a real shock to system. Suddenly I was sharing a place with four other people I don't know and had nothing in common with apart from the injury. Quite an eye opener I'll tell you.

This re-entering the 'real world' of society represents a new series of disturbing dilemmas related to the disability. Initially every situation and interaction has to be viewed from the new perspective of the disability filling life with uncertainty and anxiety. Being responsible for self entails not only a "tuning into the body" but accepting an increased vulnerability. As Randy says:

It's embarrassing to have someone do everything for you, I hate having to ask for help, but it became easier once I realized I was the expert, and began to accept responsibility for teaching my attendants.

William, an intensely self-sufficient person prior to his accident, said:

Before the accident I figured I could get myself out of most situations where I could be in trouble, but I'm more vulnerable now, it's a loss but it means I have to think things out abit more that's all.

Part of the increased self-responsibility is developing a facility to anticipate situations more thoroughly, structure unknown situations to best advantage, remain alert and prepared to problem solve. All this requires a self-consciousness not experienced by the able bodied

society. Tricia, who sustained an injury resulting in quadriplegia at the age of 17, spoke of her sudden change in attitude to responsibility after her injury, and how it isolated her from her peer group when she returned to her community 18 months post-injury:

It became blindingly clear soon after the accident that I was the only one who could see me through this, that where I go in the future and what I do with my life was entirely up to me, scary and difficult to take at that age.

Three years later, Tricia like others in this study, has begun to see these capabilities as an asset giving an underlying meaning to her life:

I'm my own destiny, whatever happens I will make it happen.

As Douglas said:

Nowadays I gain most when I'm left to work it out for myself and when I don't have anyone else to rely on, that gives me a lot of satisfaction.

The subjects emphasized the importance of the passage of time in facilitating the development of a new framework of 'disability' experience. This framework allows them to problem solve more effectively and make appropriate judgements of situations and events.

As William said:

It took at least four years before things began to click into place and life goes on fairly normally. I realised that I had built up a framework of experience, so that, if I run into problems or new situations now I know basically that I can cope - get out of situations on my own.

Brian has attained a new level of confidence in dealing with the small dilemmas associated with disability:

A lot of things you look at and at first you think you can't do it but after a few years you realise how much you have

learnt, and that you can always figure something out, and do it almost as well as before.

Larry had to put "some time" between himself and the rehabilitation experience in order to appreciate how far he had come in terms of personal development:

Far away from the hospital experience I can evaluate what I've assimilated and what I have learned and I'll tell you I'm impressed with the changes.

Learning, which to this point has been primarily instrumental in nature, begins to assume a more reflective quality. There is a sense of distancing from the event in these accounts of the experience over time. This experience brings a capacity to judge reality from the new perspective of the disability. The people I interviewed expressed a sense of personal control; of being managers of their own destiny. Whilst this does not imply that the individuals considered themselves to be rigidly in control, it conveyed a sense of involvement in planning and shaping their lives.

The perception of the disability becomes assimilated into the context of a whole life. There is a sense of "things falling into place," and "life going on fairly normally" as the experiential split is narrowed and a sense of 'self' is rediscovered. The years are seen to be filled with instructive experience. Cohen and Lazarus (1983) define coping with a disability as the operationalization of:

A variety of different strategies, such as anticipating and evaluating what might happen and what has to be done, planning and preparing, changing the environment, retreating when necessary, postponing action for maximum effect, tolerating frustration and pain, even deceiving themselves in order to feel better and to maintain hope and a sense of self-worth. (p. 612)

Life is consumed with the minutiae of assimilating the new experience, in a variety of situations, in order to gain familiarity and the confidence to move forward and in new directions. Implicit in the acceptance of self-responsibility is an acknowledgement of the realities of the disability, which once recognised, can then be integrated into a chosen lifestyle.

Redefining Disability

Initially, newly injured people are overwhelmed by the physical changes, and the emphasis is on the many problems now to be faced. Comparisons are constantly being made between pre- and post-injury capabilities and people are left reeling at the suddenness of the change. The disability is viewed from the perspective of "what one cannot do" as opposed to "what one can do." These comparisons lend themselves to pervasive feelings of inadequacy, failure and diminished self concept. In addition the individual has to contend with the response of society at large. The disability is viewed in its relationship to society's 'norm' and as a result people with disabilities consistently experience devaluation in their own eyes and those of others. The gradual rediscovery of self provides these individuals with an avenue by which their disability can be re-defined, not in terms of inferiority or limitations, but in terms of personal potential and self-reliance. Redefining the disability is dependent upon the individual's re-emerging self-confidence. A number of strategies have been identified which, when employed in the individual's own context, promote a redefining of the disability. These strategies include challenging the attitudes and stereotypes espoused by health professionals and society, and an assimilation of new sense of coherence. The latter is seen as occurring through attributing meaning

to the cause of the injury, expanding the range of available options and developing new value priorities.

Challenging Expectations "I had to prove them wrong"

Without exception the subjects in this study all considered the professionals' early expectations as erroneous and responded to them as a challenge to prove them wrong. These comments from Ian, Randy and Tricia exemplify this response:

I think if they say you can't do it and you manage to do it, there's more feeling of accomplishment. Even if you fail at least you tried, learnt from the trying, and O.K. they were right that time but it doesn't often happen!

Doctor's say "No you can't feel that" and I'll argue with them because I know differently. So I disagreed with them on a few things, they didn't like it much but tough!

That early vision of me was the motivation for me. I was going to change it and I did!

In challenging the status quo these individuals asserted their own vision, albeit a shaky vision in the early stages, enhancing their burgeoning sense of 'self' as expert through "proving them wrong". As disability becomes incorporated into an individual's self-concept, a renewed sense of purpose is experienced, giving that person the confidence to assert himself as a self-governing adult. The disability gradually becomes a component of the picture rather than the whole picture.

The subjects consistently viewed the reality of living with a disability as an "adventure" and restrictions as a "challenge." Their growing confidence gained from learning in context, combined with experience of the disability, contributes to this view of life as a

challenge. A turning point in Randy's experience was a trip to Hawaii nearly two years after his injury. Randy had never flown before his accident. He went with "two older quads," as he called them, who were experienced travellers, and their wives and his brother. As he said:

It was really important time for me to see them surviving and doing it well, we had fun, I learnt a lot from them. It was a big, big success even just from the mental aspect, my peace of mind, to know I could do it.

The perspective of disability as challenge appears to underscore future actions and contribute to the concept of spinal cord injury as significant life event rather than tragedy.

Most of the subjects described themselves as being the sort of people pre-injury who would "just get out there and do it" and identified this characteristic as contributing to their perceived success post-injury. This attitude is typified by individual comments about the wheelchair. Soon after the onset of a physical disability the wheelchair symbolizes a "loss of ability" in a very tangible fashion for both the individual and society at large. With experience, although they have not lost the desire to walk, people with spinal cord injury, quite pragmatically, begin to perceive the wheelchair as having neutral valence, or even positive value for its functional asset as a means of mobility. As Peter explained:

Not being able to walk isn't so bad, you get used to that aspect of it. Physically I feel pretty good now, I'm simply sitting down on the job more these days.

This represents a major shift in the way disability is conceptualized. The disability, instead of being experienced as a personal trait becomes a set of physical characteristics which influence function, and as such, can be

relegated to a less central role in the person's life. The disability becomes an inconvenience that has to be accommodated for in daily living but which can be mastered. Brian, in trying to explain this idea to me, made this comparison with respect to the activity of dressing:

It would be like you getting up and throwing on a whole suit rather than a pair of shorts. Like before I just have to pull on some clothes but now it takes me a little longer, a little more of a technique. It all gets faster too with experience. It's not completely like it was but it's the way it is!

However, the people interviewed in this study genuinely appeared to have assimilated an altered body image. The disability was seen as a peripheral characteristic subsumed by the value of experience which allows them to, as Tricia said:

Worry less about new situations and how strangers are going to react. All those concerns are really in your own mind.

For William being able to:

Control the essential things about my life in turn gives me peace of mind.

Dirk, who uses an electric wheelchair and requires attendant care, said:

In the last few years I've gained so much more independence, not so much physically as mentally, in the things I chose to do and how I chose to do them.

Peter makes some interesting observations about his attitude to the wheelchair:

After four years it [the wheelchair] has become a part of me, I don't even think about it now unless someone else draws attention to it, and then, if it's a problem, it's their problem not mine.

It would appear, that for Peter, competence in work and socially related activities has become foreground, while his disability has simply faded into the background as irrelevant to be recalled on rare occasions only. His son was born three years after his injury and has consequently never seen his father standing. As Peter says:

My son saw a photograph of me standing and got quite annoyed. To him I'm a normal Dad. I guess when they get a bit older they'll realise the wheelchair is a little different.

Discussions abound about the definition of 'normal' and the relationship of disability to society's 'norm.' Jung (1929) indicated that to be normal is a splendid ideal for the unsuccessful, but not for people who have more ability than the average. Wright (1983) suggests that:

The person with a disability has much to gain psychologically if physique can be looked upon in terms of its intrinsic or essential characteristics - what it permits and restricts the person to do - without basing the evaluations or comparisons with other individuals or with one's own previous nondisabled state (p. 181).

The subjects in this study who had defined themselves as 'successful' seemed also to have redefined the term 'normal,' not in terms of the visible disability, but in terms of personal involvement and contribution to family, friends and society.

Faced with these perceptions of disability which so obviously contravene able bodied 'normal' values and perspectives it would be easy for a "secondary gain, rationalization" (Wright, 1983, p. 157) judgement to be made. This reconceptualization of disability has not been formulated by assuming a Pollyanna view of the world, on the contrary, the informants had a clear understanding of the complexities,

conflicts and complications inherent in coping with a disability. The accounts obtained in this study would suggest that the losses are accurately assessed and over time an acceptance of the losses is achieved. As Brian said:

Different problems continue to be frustrating like my spasms, they flip me out of the chair sometimes when I least expect. I'll never get used to them.

Brian finds old familiar situations frustrating on occasions:

We're moving and renovating at the moment and my friends are all pulling together to help. In the old days I'd be right in there but now all I can do is sit and watch and give them verbal abuse.

Ian is well aware of the barriers to employment that exist for those people in wheelchairs:

There's so many unemployed in my industry a disabled person is unlikely to be hired even if he's actually more capable. The reality is he will need a bunch of changes and adaptations before he can work somewhere, and why would you bother going to all that expense when there are so many able bodied people available?

The consensus of opinion seemed to be that it would be all too easy to sit thinking of "what was" rather than "what is," about limitations rather than capabilities, and that the only way to proceed after a spinal cord injury was to "get out there and do it." It would appear that with experience the dominance of loss is abated. The issues of stigma are deemed as "their problem not mine." The subjects are guided by a more reflective than action oriented process, the goal of which is the restoration of a sense of personal coherence.

Regaining Personal Coherence "I'm back on track"

Coherence is defined by Antonovsky (1979) as "a generalized, long lasting way of seeing the world and one's life in it" (p. 124). There is a transformational quality to the subjects' descriptions of how life has once again become predictable and comprehensible. Dirk said:

My personality is the same as before the injury but there's been a real change.

Larry continues to reflect on the personal changes he has made:

I'm almost back to where I was before my accident, just a totally different attitude to life.

Descriptions of the early years post-injury are littered with references to the feelings of 'confusion,' 'bewilderment,' and 'loss of control' which dominate day to day existence. Subjects spoke, with relief, of their feeling of "being back on track," and their belief that "things would work out as well as one could reasonably expect from now on." Several strategies were identified as contributing to a growing sense of coherence: the causal attributions that people make for the injury, the reformulation of options, and the value changes that people experience.

Attribution theory maintains that following a threatening or dramatic event, people will make attributions so as to understand, predict, and control their environment (Taylor, Wood, & Lichtman, 1983, and van der Bout, van Son-Schoones, Schipper & Groffen, 1988). One of the ways in which an individual fulfils a need to understand why a crisis occurred and what its impact has been, is through causal attributions. Almost all the subjects in this study made reference to the cause of their accident. Some individuals accepted that the accident was

a direct result of their own behavior. Ian is now able to dismiss his accident:

If I thought too much about if I'd done that or this, it [the accident] wouldn't have happened, I'd have got nowhere. The fact is it happened because I wasn't attending too much, and the fact is too, that I've learnt something new from the accident.

Ian has been able to assign his accident to the category of a single life incident, which could be prevented from happening again, and from which one moves on. He is quick to say that, whenever possible, he will try and educate other "bikers" to behave in a more responsible manner using himself as an example of what can happen if they do not. In Ian's accident, and most of the subjects' accidents, no one else was involved or injured.

For two subjects that was not the situation, and for them, the accident was a more pressing concern. In both incidences another person was killed in the accident and the need not to be blamed for that death seemed prevalent. At the time of the interview Larry was waiting for his court date and he said:

The whole thing about the court case is for me to prove that I wasn't driving that truck. I don't care about the settlement. I'm doing fine without it. But it's really important for me to have people know that, although I know I wasn't driving and that's really all that matters.

For Tricia the accident, even three years later, was still a major concern:

I was not speeding [when I hit the horse which was loose on the road]; but as far as the world's concerned, any real proof or documents, I was the one to blame for the accident. Someone, like the owners of the horse, should have had to admit fault and nobody did. If the accident had been my fault at least I'd be able to get angry at myself but this way it's really hard.

To accept the blame is to be, in some way, labelled as responsible for another person's death. The injury takes on the connotation of the individual having reaped their just rewards, of being deserving of the disability thus adding to the stigma already associated with the disability. For Larry and Tricia, assuming some sense of mastery over the event, and deriving meaning from it, centred on their belief in their no fault stance, being believed in their assertions, and if possible proving it to a wider audience.

William, who was driven off the road by a truck, during a Trans-America bicycle race, had the opposite response. He derived comfort from the fact that he was not responsible for the accident:

I think it helped me in some way to know the accident was not my fault and strangely I've never felt anger towards the person who ran me down.

The accident, in this case, could be viewed by the individual as a random event which anyone could be unlucky enough to experience. This viewpoint, however, lends itself more readily to the interpretation of injury as 'tragedy.' Initially, whatever the cause of the accident, a person would be hard pressed not to interpret their accident in those terms. To persist over time in this interpretation would not, however, seem to be consistent with the attitude demonstrated by the subjects of "getting on with their lives."

Research (van der Bout et al., 1988 and Silver & Wortman, 1980) has suggested that for the long-disabled group, being concerned with the cause of the accident and its avoidability, and assuming self-blame is associated with high self-esteem and good coping. This is in contrast with those individual's who are concerned with the question, "Why did

this have to happen to me?" and who assign blame to others which was found to be related strongly to poor coping. This was noticeably not the a response identified by the individuals in this study. They appeared to have restructured their lives around the setback. The meaning assigned to the accident appears to become woven into the fabric of their lives, rather than remaining an isolated incidence, over which there is no control.

Whilst spinal cord injury was realistically perceived as limiting options, particularly those associated with physical activity, a wide range of options are seen as remaining. As Tricia and Dirk said:

Now the old life has gone, you don't have that option anymore so you find other options.

You tend to change I guess when you've had an injury like this, you don't have the same options, but there are other options out there, once you recognize them you can really enjoy them.

The subjects all emphasized the need to become more flexible in terms of the options perceived as being available. They advocated adapting old interests where possible, or discovering new activities through which fun and purpose could be reintroduced into life. William, who pre-injury was involved in competitive cycle racing, has transferred that interest to long distance wheelchair racing. Whilst acknowledging that for him wheelchair racing "is a poor substitute for cycling" it has caused him to develop new skills in his effort to design and construct new drive mechanisms for racing chairs. Malcolm, unable to play the piano since his accident, has been exploring the potential of

computerized instruments. For him, returning to the music world was really still of paramount importance:

I wanted to know that I could still do it, and at the time I needed a reason to get up in the morning, a reason for living, for being useful again. I wanted to know I could still sing.

Others, having survived the first two years and attained a sense of control over the daily activities of living, are able to create new options.

As Tricia and Malcolm said:

I was so worried about being independent at first, trying to make it on my own, trying to be a responsible young adult. Now I don't have to be so serious, I can go back to being a little crazy, do impulsive things, take a few risks, have some fun, that's really important. You're still limited but...

It's just like when I was able bodied I was happy, pursuing my own interests, going in the direction I wanted to go and that's what I'm doing now.

Life was seen by the subjects as something to get on with:

The injury is just something that happened, no use dwelling on it, life goes on and the only option is to make the best you can of it.

Exploring options, getting involved, being productive, efficient or good at something on one's own terms were seen as building confidence and self esteem. It seems that this comprehensive positive viewpoint involves a diversity of value changes. The scope of values is enlarged. A wider variety of sources of satisfaction and meaning become available. Tricia acknowledges the process she has experienced over the past three years:

It's like you grew up, developed new interest in people, your education, new hobbies. So you never give another

thought to what you thought was so important when you were younger. When you grew up you changed and that's what has happened to me.

In describing this personal growth to me, Tricia talked about realising that she still had something to offer in relationships, that they could still be reciprocal. She stressed the importance she now places in not taking people for granted and being clear in her communication with people. Another value shift occurs when the person becomes convinced of the fundamental importance of non-physical values such as kindness, cooperation, doing one's best, patience and relationships. Physical appearance is felt to be less important for the evaluation of a person than personality. Ian said:

At first I thought I'm not physically attractive anymore, and that was of real importance to me - my physical appearance but I don't worry about that any more. I realise now that a lot of things that make a person attractive aren't simply physical. It's more in your personality, your mental attitude, the way you act towards others.

Dirk also described the change of values he has experienced:

All the things I thought were really important before I now find were not. Like at first what bothered me was that I wouldn't be able to throw a ball to my sons anymore. You think at first that you've lost more than you have. We're much closer in a different way now. Where you come from is the heart and I think just that insight is a gain.

For others the meaning gained was self-knowledge or personal growth.

Tricia contrasts the way she saw herself before and after the accident:

I used to be a typical self-centred teenager always bitching about something, but now life means more, and I appreciate people so much. I'm more laid back and I communicate in a real sense.

Brian felt, during the interview, that he had difficulty putting his emotional, intellectual and, in a sense, spiritual experience into words. One way he described it was:

I looked at my life and realised just how precious it is and how a easily it can get wrecked. Sometimes I feel like a totally different personality my attitude to life has changed so much.

Typically people reordered their priorities, giving low priority to competitive pursuits, routines and schedules and superficial relationships. Larry, whose life as a fisherman before his accident, bears little relationship to his life now said:

I've come to realise that you can only do your own personal best. I set my own goals now. I never had any goals before. When I achieve them it makes me feel good about myself better than I ever did before my injury.

Dirk orders his life differently now:

I'm busy and I do keep to schedules I set for myself but I don't let them rule my life like they did before. I don't get uptight or flustered about things anymore because the things I used to think were so important seem trivial after going through all this.

For some people these value changes took a different form. There are those, for whom the experience has been so positive, that I was left with the impression that they would not relinquish the disability even if they could. As Larry and Brian said:

Before my accident I thought I was going to be a fisherman all my life with all that that life means - lots of money, seasonal work, smoking, drugs and booze. I'm almost grateful that I had the accident, the change in me and my life has been so positive.

My basic lifestyle has changed, most of life revolved around physical things before, pretty superficial really, now all that's changed. It's changed the way I used to think about life, my job, the way I treat people who are close. I completely enjoy this side of the fence, it's a lot better.

The value changes described and attributed to the injury experience appeared to enable people to restructure their relationships along more satisfying lines, to maximize their abilities rather than their disability, and contributed to a sense of 'getting back on track.' Life, as described in these accounts, is certainly not one based on disappointment, second rate goals and expectations or diffusing frustration. There is a sense that many of the physical things that dominated life before the injury, now, not only did not matter, but would not matter if the person could in some way return to doing them.

The subjects, in refuting the image of disability projected by health professionals and society, define their own range of capabilities based on personal experience. Actual limits are determined and alternative options are sought. It appears to become progressively easier to say, and mean, that the disability does not matter much most of the time.

Establishing a New Identity

There is a temporary loss of identity following spinal cord injury, described by one person as "like being in a holding pattern," which is attributed more to the distortion of the relationship of the individual to significant others, established roles and society's 'norm,' than to an internal change. Identity can be defined as "the fact of being the same in all respects" or "a statement of equality which is true under all conditions" (Webster's Encyclopedic Dictionary, 1988). Identity can be

perceived as a complex and unique combination of the individual's own self-concept and life history and the concept held of the individual by others. A person's identity is an integration of both the internal and external experiences and is closely related to identification with society. This identification involves the many roles which a person assumes, for example, spouse-lover, parent, employee, team member or church member (Vash, 1981). These roles identify and describe the individual as a social being and are central to a person's self-concept. A crisis is experienced following traumatic injury because the familiar identifications with the majority 'able-bodied' group appear to be irrevocably lost. The loss of roles associated, at least initially, with severe physical disability is perceived as excluding the person from significant social participation and devaluing them.

'Successful adjustment' to disability appears to involve the establishment of a new identity. This identity evolves from a desire not to conform to the values and standards of the majority, but from a reassertion of purpose, achievement of personal goals, formulation of relationships, and the successes and failures common to adults in general. The individual's life, temporarily interrupted by a significant life event, is seen as regaining momentum and a degree of consistency with their pre-injury experience. Establishing a new identity is achieved by making comparisons with others by which self-esteem can be enhanced, by association and dialogue with a peer minority, by creating intimacy with significant others and new ways of interacting with society.

Comparison With Others "I've got a lot going for me"

Comparison with others was manifested in several ways. Firstly, and possibly the most extreme, the comparison made, by three individuals, with someone who had died at the time of the accident and which the survivor had survived:

My friend died and I almost died too - I just made it. I'm pretty lucky that I'm alive. I got a second chance and I have to make the best of it.

There is no question that compared to someone who died, one is indeed better off. Two subjects acknowledged that this was a strategy that they invoked, particularly during the early acute stage of recovery, when their own fears of dying as a result of the injury were strongest. It may be that at that stage invoking the 'worst world scenario' fulfilled the purpose of expressing their own fears:

One of my friends got killed that night and when I begin to feel really sorry for myself I start to think back and realise how lucky I am.

Several years later the informants still gain meaning from the comparison:

She would have done something, made something of herself, helped other people I know she would so I start thinking I shouldn't feel so bad and snap out of it.

At this stage the 'friend' as a comparative tool is largely a figment of the individual's imagination, but continues to act as a motivation or yardstick against which the individual's capabilities can be measured.

In some instances a "dimension" (Taylor et. al., 1983) may be selected on which the comparison is made so as to make the self appear favorably. This is a flexible method of making comparisons between the

attribute and the "target" (Taylor et al., 1983) and can be chosen as the need arises. The following statements, made by Larry and William, are examples of this type of comparison:

One of my friends never accepted his injury and he's still just sitting around. It's important to me to accept it with dignity otherwise you end up like him bitter, frustrated and angry.

I would rather be in Canada like this in a wheelchair than in a Third World country watching my family starve.

The burgeoning new identity seemed to be reinforced, for some of the subjects, by looking around at their peers, both disabled and able-bodied, and realizing that they have advanced beyond them and even beyond their own expectations. This strategy was used on occasion by all the subjects during the interviews, for example, Larry said:

Being a quadriplegic must be that much harder. Sometimes when I'm with my friend I almost feel bad at the things that are so easy for me, like throwing myself out of my wheelchair onto the chesterfield, which is almost impossible for him to do. I'm in a wheelchair and I'm feeling bad for someone else!

Some subjects described how observing others who were not doing as well, despite having the same level of injury frustrated them, but at the same time the comparison functioned as an acknowledgement of their own ability. As Douglas said:

I get frustrated when I see guys about my age being heavily dependent on their spouses or parents after the injury, not reaching their potential or taking responsibility.

Most of the subjects were conscious that the injury had shifted the direction of their lives in a positive sense. The injury, for Tricia, has resulted in her achieving the goals of living independently from her

parents, travelling and pursuing higher education. These goals were only formulated since her injury and bear no relationship to her pre-injury lifestyle. She frequently compared her current lifestyle and interests with the image, as represented by her peer group in her home town, of how she might have been.

These examples illustrate a form of comparison described by Taylor et al. (1983) as "downward comparison". These comparisons have the psychological advantage of making the person feel good about the situation. Taylor et al. (1983) argues that in situations in which circumstances cannot be remedied, or frustrations alleviated, through instrumental action people will utilize the strategy of 'downward comparison' to preserve their self-esteem.

For Randy, discovering the range of his capabilities - his personal best - through trial and error rather than getting caught up in external definitions of disability, or comparisons with others, proved a more effective approach. As he said:

You have to see yourself as an individual who's got so much disability and you've got to keep on struggling with that. I mean there are people out there who have more than you and yet are worse off than you, I mean they just give up. I think its best to go your own way and try not to compare yourself with others.

Evaluating the situation against that of people who are doing better was another strategy which proved helpful for some subjects in creating a new identity. Brian, who sustained the same level of injury as his brother-in-law, a quadriplegic whose injury had been many years before, saw the comparison as being totally beneficial for him:

I think it was really hard for some of the guys in rehabilitation who didn't have the example of someone like Greg. Through Greg I knew immediately all the things I could do in a wheelchair. I just switched right away, he was a real inspiration to me, in fact he still is!

Douglas, who now counsels newly injured persons, acknowledged the influence of one individual in particular:

I think I found myself emulating him even years later when I was talking to fresh injured people. Yeah, he left a big impression. He was there as a goal for us to strive for and just the way he carried himself and the stuff he said made sense.

Taylor et al. (1983) have called this strategy 'upward comparison.' This type of comparison has the benefit of providing information that is potentially useful for improving an individual's own outcomes, but it has the disadvantage of making a person feel dissatisfied about their situation. Making 'upward comparisons' seems to complement the theme of the experience of spinal cord injury as 'adventure' or 'challenge.' The variety and prevalence of comparisons in the data suggest that they are rarely confined to one type for each individual, but are in fact, multidimensional and serve various needs simultaneously. Comparisons are made primarily to restore or enhance self-esteem but they also contain informational and motivational components.

The Peer Group "Brothers in Arms"

Much has been written about the advantages of self help groups - positive aspects including the dimensions of knowledge, therapy and skill acquisition - in promoting adjustment to a disability. The subjects in this study all expressed a willingness and interest in talking to others injured more recently than them. They all felt strongly that they had

useful information to share, and that as "old hands," they could act as role models for individuals struggling to reassert a sense of identity following the injury. In reality, they were rarely in a position to act as an expert peer as there was no purpose for them to return to the rehabilitation setting, and they were leading busy lives pursuing their own interests. All the subjects acknowledged how helpful they had found their associations with expert peers over the years. Their peers were described as sources of credible information and instruction, as Peter said:

I used to like talking to other guys who had the injury before me. When they told you something it seemed more believable and you could see the sort of things that were possible.

Most felt that it would have been particularly helpful to have that sort of contact at the time when they were discharged from the rehabilitation centre.

All the subjects spoke of their close and valued ties with others who shared the experience of spinal cord injury. As Douglas said:

Sometimes I think its like Viet Nam vets - the camaraderie. Because you've shared a common catastrophic experience and gotten over it to some degree, right away you have something major in common. There's a whole bunch of stuff that can remain unspoken and it's almost as if its a closed circle. Amazing also how many of the same views we hold.

To the 'outsider,' and this includes in my experience those health professionals working in rehabilitation, the visible disability can become, at least initially, the outstanding characteristic of the relationship. The person with a disability has to embark on a gradual process of education to reverse this initial impression. The 'camaraderie' eliminates that need giving each individual's personal qualities a chance

to assume ascendancy. Those people, who had developed a predominance of friends who shared the injury in common, were those who were involved with competitive disabled sports. As Peter, who returned to playing tennis after his injury, said:

Most of my friends are wheelchair tennis players and I see them all the time. My wife and a couple of old friends play with us. I've made a lot of good friends since my accident. It's easy we've shared the experience.

Becoming disabled is to suddenly be thrust into membership of a minority group, the major criterion for which is, that you are sitting down. It would appear that through identification with the minority group there is an awakening of pride, a sharing of assets and abilities and a lessening of the importance of belonging solely to the majority group. Accepting the disability does imply a certain feeling of kinship with others who have the same disability although not necessarily everyone in a wheelchair.

Wright (1983) suggests that acceptance of one's disability is a prerequisite, not only for group identification with other persons who have disabilities, but also with others who are regarded as able bodied. Oliver et al. (1988) in their study found that clearly some people did not wish to make friends with other disabled people "preferring to be with people who were quite normal" (p. 63). Some authors contend (Wright, 1983 and Trieschmann, 1988) that this preference indicates that the person with a disability wishes to be considered non-disabled. Phillips (1985) calls this response "success-as-normalization" (p. 50) characterized by an affiliation with "normals," a striving to "overcome" the disability, and disaffiliation from those perceived to acquiesce to the

"cripple role." I did not find evidence of this type of response in any of the subjects' accounts of their experience, which suggests a sophisticated level of adjustment to their injury had been achieved which was compatible with their self definitions of success.

Intimacy With Others "Relationships are more important"

Positive social experiences were seen as supporting individuals' sense of continuum and identity. Relationship with others, spouses, family and friends, is central to the human experience. A sudden disabling injury can seriously disrupt, at least temporarily, the patterns of relationships. For Randy the loss of friends in the early phase was understandable but no less distressing:

At first people noticed a big change in me, I mean I was really depressed. Maybe that's why alot of my friends got scared and stopped seeing me, they couldn't deal with the big change in my personality. I pretty well got my old personality back now and I have developed a whole new set of friends. It all took a long time but what a difference it makes to life.

Ian admits:

To being very hard on his wife during the first three years. I had this thing that I couldn't see how anyone in a wheelchair could still be physically attractive. I didn't know what the hell was going on or who I was anymore. I thought basically my wife would be better off without me.

As his wife explains:

He was not an easy person to get along with when he came home. He misinterpreted things and he was very defensive to the point that everything got turned around. It was like he was trying to prove he wasn't worth being around, trying to push me away.

The resolution of the problem occurred slowly in their case as a result of Ian's "changing attitude." He began to develop a different perspective on many aspects of his life. As he explains:

I really did a lot of thinking and somehow I came to appreciate my relationship with Nairn more, we talked more about everything. My friends stuck around, willing to help and I got so I was able to ask for help and actually enjoyed it.

The individuals I interviewed described themselves as "old hands," they acknowledged the realities of their disability and appeared to have integrated it into their chosen lifestyle. It is as though these individuals recognize that without the disability they would be different from what they are and there is no desire to be any different. Relationships with spouse, friends and children are appreciated and nurtured in a more conscious manner than pre-injury. As Peter and Tricia said:

When I think back I realise that I took my wife and friends pretty much for granted.

You really get to appreciate people more. When I make a new friend these days, you know work through all the stuff about the injury that they don't know, I figure they really want to know me and that's important. I put alot more effort into my friendships these days.

Priority is given to relationships, personal projects, or just plain enjoyment of life. Reflected in these statements is a sense of living life to the full. Ian said:

I feel my daughter (born after the injury) is a direct result of all the changes caused by my injury, that I'll be a better Dad than I would have been before, and man, that's positive.

Douglas observed:

Relationships are more important and I think I'm more mature in those now too.

Dirk, who experienced some major lifestyle changes before achieving his current sense of coherence said:

For everything's there is gain. For everything you've lost there's something gained. My family's grown stronger, more closely knit just because we know we're more vulnerable.

Tricia, although knowing she can never recapture the teenage years affected by the injury, feels:

I don't have to be so serious about my life now. I think I'm getting back some of the carefree attitude I had as a teenager before the injury.

Being partnered, involved with family members, having a circle of close friends were all considered important contributors to their sense of identity and self-worth. But as Douglas cautioned:

You shouldn't rush into making changes or forming new relationships too early or they will be based on all the wrong things. You need to establish yourself a bit first, sort some things out.

For some people the struggle to regain a sense of identity is made more difficult by the reaction of old friends and family members to the injury. As Randy explained:

At first everyone came to visit me, then after a while many of them dropped off. They just couldn't hack seeing me like this. Even my brother had trouble, he's only just started coming around again.

Friends who were still able to see the 'inner' person despite the distraction of the physical changes were valued by all the subjects. It

was important to be treated just "the same as before." Ian felt that his old "biker" friendships had been strengthened by his willingness to ask for help and his recognition of "how important those people are."

Individuals with higher injury levels, dependent on others for assistance, rejected accepting the proffered help of parents and syblings, preferring to live with attendants. It seemed that these individuals instinctively knew that the dynamics of these relationships would be irreparably altered by the stresses and strains of providing constant care. As Randy said:

They [the rehabilitation professionals] wanted me to go and live with my parents but I'm 35 years old and I just couldn't see doing that. It would be like being a child again, not to mention the burden I'd be on their lives.

Inherent in this account is the assumption, on the part of the rehabilitation professionals, that the family situation was the appropriate place to which to return the person with spinal cord injury. On the other hand, the choice of living with friends or care attendants had been the individual's, and as such more compatible with the adult role in society.

Interactions With Society "It's their problem not mine"

One of the responsibilities accepted by the subjects, particularly those with more severe disability, was the need to become, as Thomas (1982) called it, "a skilled co- manager of interactions" (p. 59). Creating a successful social image contravenes the societal image of passivity and acquiescence. Examples of this skill can be seen in the following statements:

I can get through to people now because I initiate the conversation. Once I get that wall down they forget the obvious, but the disabled have to make the effort.

You know you've made it when you are able to deal with the public on a one to one basis, and you find yourself not caring about the way they look at you because you know it's their problem not yours.

I realised I was being judged on how I presented myself not on the chair, that's soon forgotten by most people. That realization helped me gain confidence and helped my communication with people.

The issues contained within these statements revolve around the fact, that in general, able-bodied people tend to see and respond to the wheelchair before seeing and responding to the individual. I was surprised that the individuals I spoke with accepted without rancour the demands on them to neutralize this first impression, and the effort required to educate the public. This required an acceptance of the existence of stigma. Counteracting the stigma seemed necessary for these individuals in order to be successful in sustaining a new identity. The subjects felt that by achieving this goal, "making someone forget about the wheelchair," the able-bodied person involved gained an understanding of their true 'inner' self. Douglas recalled how during his first year back at college he struck up a friendship with a young woman from France who was also attending classes. He said:

That was the first time any female was interested in me not because they wanted to find out about the wheelchair or look after me, but because she was interested in what I had to say in an intellectual and emotional sense. It really did my self-esteem good.

Mead (cited in Miller, 1982) suggested that as a society shapes the self, so the self shapes society. This seems an apt description of the experience of these individuals in managing their social interactions.

Thomas (1982) says:

To become disabled is to be given a new identity, to receive a passport indicating membership of a separate tribe assigned at the moment of injury. It involves a social learning process in which the nuances and meanings of the identity are assimilated. (p. 39)

Part of the 'social learning process' is re-establishing roles and purpose in life. Following the injury most individuals experience a loss of roles and exclusion from significant social participation. These losses deprive them of essential functions that underlie their sense of self-worth, self-concept and identity. North American society rewards people according to their economic and material possessions. In this type of society persons with disabilities are judged as having little to contribute. It appeared that, as the impact of the disability diminished, these individuals began to think of themselves in terms of their former social roles. For some, like Ian, resumption of these roles occurred relatively easily. He remained married, was discharged to the house they purchased before the injury, and returned to work ten months after the injury.

Gainful employment which is deeply ingrained in the North American society's definition of normality, and which is still considered an important outcome of successful rehabilitation, did not emerge from these accounts as particularly central to the experience of spinal cord injury. Several of the subjects were working, full-time or part-time, at the time of the interviews, in situations they valued and considered to be productive, but it did not appear that working contributed in a major way to these individual's feelings of self esteem. For Ian, returning to his pre-injury profession soon after the injury had been important, more for the valued changes he and his spouse were making in their

lives, than for the status of working. His employment allowed his spouse to gain a professional education and helped anchor him back in the context of his life during the first two years post-injury:

I was lucky to have a profession I could go back to. They were really good, took me back initially part-time, made the necessary changes. It had a lot to do with how well I accepted [the injury] in the end.

However, over time his attitude towards work has undergone a change:

I realise now that it felt really good to help Nan out but I'm really only working now to support my other interests. That's so different from before when it seemed so important to be working. It definitely isn't my main interest in life now, I have so many other things going on.

Randy, however, described his distress when he realised that he might never be employable again. He says:

I did a lot of television watching that first year after I was discharged, didn't know what to do, absolutely no purpose in life.

He was contacted by a Foundation funded to customize computer systems for individuals' needs. Through the help of their student volunteers Randy became proficient at word processing using a morse code entry system. As he said during our conversation: "Anything you can do on the key board I can do probably better!" The Foundation assisted him to gain a realistic familiarity with the existing employment market, provided a safe environment for him to learn and practice the skills he needed, and expanded his social network. Building on some accounting courses he had taken to enhance his business before his injury, Randy took additional courses and is currently employed "doing

the books" for a company. He acknowledges that at first the struggle to master the computer seemed too much, and that he was motivated primarily by the Foundation volunteers. A sense of purpose only came later when, it became apparent, that he might be able to put the new skills to practical use.

Prior to the injury, purpose, for the subjects, was associated with tangible achievements, such as, owning a house, being employed, doing a cycle marathon or achieving first place in water skiing competitions. These tangible criteria were accepted as part of the social ideal of normal. Post-injury, purpose and success were re-defined in terms of specific physical, social and personal criteria, such as establishing an independent living situation for oneself with the aid of an attendant, getting into the driver seat of a vehicle, overcoming the obstacles to travelling to Hawaii. More emphasis was placed on the satisfaction of achieving a personal goal than on aspiring to goals dictated by an external source. William returned to his former job soon after his injury motivated, at that time, by "the old work ethic" and a feeling of "not wanting to be a burden to society." He had since "retired" and is exploring his skill in metal work in a workshop he designed and installed in his garage. He, like many of the other subjects, is firmly convinced of the need to have a purpose, "something that is important to you to do." The purposes they described are as diverse as the injuries and the individuals themselves. These responses to disability suggest that individuals create meaning by renegotiating society's definition of normality and asserting their own criteria for perceived success.

In comparing their process with others, the subjects with high levels of injury recognised that they required a longer time frame in

order to reassert a sense of identity. They attributed this longer time frame as much to other factors - such as, break up of a marriage or intimate relationship, loss of independence in business and no longer being able to live in their own house which contributed to the disorganization of their previous lifestyle - as to coping with the physical disability and its consequences. These compounding factors were not experienced, to the same degree, by those individuals who had sustained a lower injury.

Several studies support this opinion. Oliver et al. (1988) found social and financial support to be of more significance than level of injury when related to positive view of self. Green et al. (1984) demonstrated significantly higher Moral-Ethical scores for the respondents, all of whom were at least four years post-injury, who required more physical assistance. They surmised that perhaps the higher scores reflected a more intense process of self analysis, and searching for meaning of life, on the part of those persons with severely limited function.

These subjects initially experienced radical loss of all their familiar roles, and were required in the course of becoming 'successfully adjusted' to create and adopt new roles. These new roles evolved from achieving independent living situations. Independent, in this context, meant living, not in an institution, but alone or in a group home. In all cases, these individuals were dependent on the assistance of an attendant for hygiene, dressing, and in some cases eating, transfers and driving. The dictionary definition of independence is to be "free from the authority, control or influence of others" (Webster's Encyclopedic Dictionary, 1988). This is not a difficult definition to accept with relation

to persons with spinal cord injury but it becomes controversial for the persons involved in claiming independence when the connotation of ability to survive alone without the aid of others is added.

It is this connotation which pervades society's ideal and underscores the philosophy and goals of rehabilitation programs. In this setting 'independent' is used as a synonym for "unassisted," for example, when referring to independent transfers. The concept of independent living has been redefined by these individuals to mean simply freedom of decision making and the power of self-determination. In redefining 'independence' these individuals have carved out another role for themselves, that of expert. This role, is an essential aspect of being 'successful' as it requires them to direct others in their care. As Randy describes it:

This is my home, I share it with another person and we're in charge of what goes on at all levels. We hire and fire the attendants, budget, decide what food to buy. We set the rules. They are being paid to help us so we're not a burden to anyone.

This view of self as expert was expressed by others as essential to a sense of identity, but difficult to achieve particularly during the rehabilitation phase. As a minority marginalized by society a level of confidence is required to overcome those people in rehabilitation settings, professions or agencies, who assume the right to determine the direction and quality of other people's lives. Douglas, who needed financial assistance to achieve his goal of becoming a history teacher, said:

You've got to get to know the system. You have to be really persistent and know what you want. A big mouth helps! You just have to keep at it, not let yourself be put off because they tell you it's not possible.

Ian, having read about some new medical advances in the area of fertility and spinal cord injury, changed physicians three times until he found one who would help him explore the new possibilities. As he says:

The average family doctor knows nothing about spinal cord injury. You have to find one who is prepared to listen to you as the expert on your own body.

In some respects, the subjects, in their efforts to establish a new identity following spinal cord injury, appear to have "renegotiated societal definitions of normality" (Phillips, 1985, p. 50). The emphasis on 'being normal' which pervades the subjects' accounts can be represented by these statements made by Tricia and Larry:

I live a normal life, I don't feel disabled anymore. I feel that I'm doing things that most people do. I have a job like everyone else, I enjoy the same things I always did, do the same chores, have the same problems everyone does.

I mean normal as an able bodied person whether they are screwed up on drugs or what they are still normal - I'm relating normal to being just the way you came out of your mother - living a life.

Belonging to the majority, or the able bodied society, means sharing any number of factors such as race, religion, position, education, inherited traits and talents. These factors are not physical but they contribute to a person belonging to the majority group. The subjects in this study appear to be saying that these factors do not change just because you are sitting down. Thus the continuity of 'adjustment' to a disability with the human development of people-in-general is stressed. The development tasks are the same; the unique aspects and different situations created by the reality of the disability are of secondary importance. The experience is seen as presenting unexpected potential

psychological and spiritual learning opportunities. Achieving a sense of identity following a disabling injury is a complex integration of both the 'inner' and 'outer' selves, it involves an embracing of the experience of disability. It is perhaps attained when the frustrations, conflicts and stresses resulting from the physical disability have been minimized, self-esteem has been reasserted and some purposeful interactions with society have been restored. This new identity demands that they be accepted for their nondisability characteristics and that they be afforded all the rights and responsibilities inherent in adulthood.

The subjects in this study describe a number of specific social and personal accomplishments, the achievement of which has contributed to their conceptualization of the injury and by which they define successful rehabilitation. It becomes obvious that there are a diversity of meanings attributed to the experience of spinal cord injury and that there is no single definition of successful rehabilitation. Learning to live with a disability resulting from spinal cord injury, as it has been revealed through the subjects accounts of their experiences, may be regarded as a intensely personal transformative learning process.

Chapter Five: THE EXPERIENCE OF SPINAL CORD INJURY FROM THE PERSPECTIVE OF TRANSFORMATIVE LEARNING

The purpose of this study was to determine how people conceptualized their disability following spinal cord injury. The questions asked during the interviews did not directly address the subjects' experience from the perspective of learning. Through analysis of the data, that is, the accounts of the subjects' experiences of traumatic spinal cord injury and the meanings they have attributed to the experience, it became obvious, however, that these individuals were engaged on a unique learning process. The quality and complexity of the learning process suggested by these results denies the images conjured, or connotations engendered, by the terms 'adjustment' or 'coping' which are commonly used to describe this process. In contrast, the results suggest the attainment of new individual consciousness and personal growth which transcends the limitations imposed by physical disability and which propels the individual on to a full and satisfying life. Over the years I had become increasingly aware of the limitations of the rehabilitation service provided, when compared with accounts of the experience shared with me by people who considered themselves 'old hands' in terms of living with spinal cord injury. In conducting this study it became clear to me that an alternative education theory was required which could inform the learning process being described by the subjects. Mezirow's theory of transformational learning is considered to be such an alternative.

The purpose of this chapter is to explore Mezirow's theory of transformative learning in relation to the conceptualizations of the

experience of spinal cord injury identified in this study. I selected Mezirow's work on the basis of it's ability to contribute to the understanding of the learning involving changes of consciousness, as exemplified in the meanings attributed to the disability resulting from spinal cord injury. It is hoped that the introduction of the theory of transformative learning, in the context of adjustment to a severe and sudden disability, will stimulate and assist in the development of a more holistic, individual centered approach to rehabilitation practice, which recognises the adult capabilities and the centrality of the individual's concept and definition of 'success.'

Three themes, consisting of a grouping of conceptions of the experience held by the subjects, and by which meaning was made of the injury, were identified. These themes were interwoven in the subjects' ongoing experience of the injury, and the strategies associated with each theme were frequently utilized simultaneously in meeting the day to day challenges of living with disability. Rediscovery of self was achieved by gaining knowledge and control of the injury and it's ramifications, rejecting the limits and constraints imposed by health professional expectations and institutional protocols, and by accepting self-responsibility. Disability was redefined by each individual in relation to the context of their lives, lifestyle and society in general. The process of establishing a new identity in relationship to others and society had a 'conscious' reflective component and appeared to share similarities with the psychological concept of 'self-actualization.'

These themes bear little relationship to the instructional content received in the formalized rehabilitation setting, and defy explanation through the traditional learning perspective of skill acquisition and

behavioral change which dominates rehabilitation practice. The data yielded a way of understanding the experience of spinal cord injury which is not adequately expressed in the literature or in the provision of rehabilitation programs.

Rehabilitation service provision has been directed primarily by the biological science or medical model approach, the focus of which has been the remediation of an underlying pathology. Within this system the individual is viewed primarily as the passive recipient of information about the skills and behaviors required to maintain optimum physical health following severe injury. Furthermore, if the person does not seem to participate at the level at which he is judged, by the health professionals involved, to be capable, that individual is labelled 'unmotivated.' It is deemed the person's fault, that is, they are lacking the inner drive to get better.

The fallacy of this approach has recently begun to be recognised and the educational or health care model of service provision has been developed as an alternative. Within this model the process of rehabilitation, in an institutionalized setting, is seen as one of facilitating the restoration of balance among the psychosocial, physiological and environmental factors in an individual's life (Trieschmann, 1988). This model, however, is still premised on a behavioral orientation. Trieschmann (1988) suggests that:

The rehabilitation process should provide the individual with training in skills needed to function as a self-sufficient adult in the family, work setting, community, and society in general. Outcomes of this process need to be measured by degree of community integration using the same basis of success as apply to nondisabled persons. (p. 42)

The focus of the rehabilitation education effort, according to Trieschmann, needs to be "survival, harmonious living, and productivity" (p. 42). This proposal is supported by the findings of this study. The three components "survival, harmonious living and productivity" share respective commonalities with the themes of rediscovering self, redefining disability and establishing a new identity. However, as Trieschmann (1989) regretfully concludes, "this [focus] is consistent with our *philosophy* but not our *strategies* (operational procedures) of rehabilitation" (p. 42). In effect, despite the increasing awareness of the educational nature of rehabilitation practice, it continues to be driven by the expectations and definitions of success of health professionals. The complexity of a person's totality which involves issues such as values and motives, contexts and frames of reference, and the centrality of consciousness in human experience is not addressed (Taylor, 1989).

Adult education has been instrumental in shifting the focus in studies of learning, from an emphasis on the material to be learned, to an emphasis on the experience of the individual in the learning transaction. This growing recognition of the centrality of the individual in the learning process has led to some interesting recent developments in adult education. Some conceptualizations of learning have emphasized conscious awareness and changes in consciousness as integral to the practice of adult education. One such adult educator is Mezirow (1978, 1981, 1985a, 1985b, 1985c, 1988, 1990) who has proposed a theory of transformative learning based on his observations and participation in practical adult education situations.

Adult educators also share the viewpoint that adult learning as a transactional encounter is essentially a lifelong process (Brookfield, 1986). The concept of "disability career" was used in this study as a method of reinforcing the idea of disability, and the learning associated with it, as an ongoing process assimilated into the continuum of a person's life. Carver (cited in Oliver et al., 1988) sets out the rationale for such an approach:

A career in disability refers to the course or progress through life of any disabled person insofar as he encounters problems or handicapping conditions related in any way to his disability. A person's progress may be affected ... in practical ways and/or in the way he thinks about himself or others. This concept of career is a broadly comprehensive one and implies that the individual is actively and repeatedly involved in the definition of his problems and in search for solutions, and, like any other career, it will comprise a succession of interactions with his environment, both physical and social. (p. xi)

The term 'rehabilitation' is commonly used, and indeed was used initially in this study to suggest that a finite point of successful rehabilitation is reached. The subjects relegated the term 'rehabilitation' to the provision of formalized program experienced during the first two years post-injury. Inherent in the term 'rehabilitation' is the sense of trying to restore a person to a previous level of functioning. "Going back" to a previous state is not the direction suggested by the subjects' accounts of their experience. It is not the natural direction of growth at any age and denies the utility and value of the disability experience as a potentially powerful stimulant to psychological growth. If the term 'rehabilitation' were to be substituted for phrases indicating 'human

development' then it might be that the subjects in this study would say that they are never fully 'rehabilitated.' As Brian said:

If you're strong enough to survive in the first place and it gets your attention, it seems to me it is the beginning of a great adventure.

Disability, viewed in the context of a life continuum, becomes sublimated over time by the real business of "getting on with life" and "doing the best with what we've got." By considering the injury as a component of the continuum of a person's life, rather than an isolated incidence, it can be integrated with the unique historical and contextual framework of each individual. The state of adulthood can never be fully realized, and it is not a question of an adult acquiring a set of fixed competencies as promoted by a more 'reductionistic' approach to learning. Central to the idea of lifelong process is the notion of praxis as alternating and continuous engagements by learners in exploration, action and reflection (Brookfield, 1986). This innovative kind of learning can occur without professional intervention and is premised on the adult's ability to make meaning of an experience.

According to Mezirow (1990) to make meaning means to make sense of an experience, that is, to make an interpretation of it. He defines learning "as the process of making a new or revised interpretation of the meaning of an experience, which guides subsequent understanding, appreciation, and action" (p. 1). In proposing a transformative theory of adult learning, Mezirow perceives the nature of these meanings and how they can be changed to allow exciting possibilities for realizing meaning and values, as the central focus of the theory. Transformative learning is defined as "the process of learning

through critical self-reflection, which results in the reformulation of a meaning perspective to allow a more inclusive, discriminating, and integrative understanding of one's experience" (Ibid., p. xvi). The learning dynamics, incorporated in this theory, as a specific type of learning with specific goals has been called perspective transformation.

The concept of perspective transformation, a form of change of consciousness, is the core concept around which Mezirow's (1978) emerging theory of transformative learning has been organised. It was derived from research with college re-entry women. At that time he described perspective transformation as:

Learning how we are caught in our own history and are reliving it. We learn to become critically aware of the cultural and psychological assumptions that have influenced the way we see ourselves and our relationships and the way we pattern our lives. (Ibid., p. 101)

The dynamics of perspective transformation appeared to include the following elements:

(1) A disorienting dilemma; (2) self-examination; (3) a critical assessment of personal internalized role assumptions and a sense of alienation from traditional social expectations; (4) relating one's discontent to similar experiences of others-recognizing that one's experience is shared; (5) exploring options for new ways of acting; (6) building competence and self-confidence in new roles; (7) planning a course of action; (8) acquiring knowledge and skills for implementing one's plans; (9) provisional efforts to try new roles and to assess feedback; (10) reintegration into society on the basis of conditions dictated by the new perspective. (Ibid., 1981, p. 7)

The individuals in this study employ a number of strategies based on their conceptions of the experience of spinal cord injury and by which they rediscover a sense of self, re-define disability and establish

a new identity. These strategies are represented in this general statement of the elements of perspective transformation. The strategies demonstrate a movement, by each individual, toward a new perspective which will prove more integrative of the experience of disability and facilitate resolution of their disorienting dilemmas.

Perspective transformation may occur through a series of gradual transitions or through sudden insight (Ibid., p. 7). "Disorienting dilemmas," for example, sudden loss of a partner or a job, betrayal or rejection, change of residence, of which old ways of knowing cannot make sense become catalysts or "trigger events" that precipitate critical reflection and transformations (Ibid., 1990). The experience of sudden spinal cord injury has been referred to as a "significant life event" in the course of this study, that is, an event which has a disruptive effect on a person's life. As has been discussed in Chapter One what makes life events significant is the meanings attached to them and the resulting "learning process which occurs includes acting on these insights" (Ibid., 1990, p. xvi). The "trigger event" in the case of the subjects in this study is traumatic spinal cord injury and the resultant disability. It is a catastrophic experience which calls a halt to life as previously known, 'demands attention' and a change in the individual's perspective of reality. This reality is founded on a structure of psycho-cultural assumptions within which new experience is assimilated:

There are certain challenges or dilemmas of adult life that cannot be resolved by the usual way we handle problems... life becomes untenable, and we undergo significant phases of reassessment and growth in which familiar assumptions are challenged and new directions and commitments are charted... Resolving these anomalies through critical analysis

of assumptions behind the roles we play can lead to successive levels of self development. (Ibid., 1988, p. 101)

These familiar assumptions, deeply embedded in the individual's history, form the grounding of an adult's experience and constitute a frame of reference which serves as a context for construing meaning.

Mezirow (1990) has differentiated two dimensions of meaning which need to be taken into account when considering adult learning. These two dimensions are meaning schemes and meaning perspectives. During the course of their development children are socialized into ways of perceiving reality through meaning schemes and perspectives (cognitive structures of assumptions) that are uncritically assimilated from people who are significant in their lives (Ibid., 1990). Meaning schemes are habitual expectations, implicit rules for interpreting which govern, for example, cause-effect or event sequences. Examples of such a meaning scheme would be expecting food to satisfy hunger, or that the sun will rise in the east (Ibid., 1990).

Meaning perspectives are made up of higher order schemata, theories, beliefs, prototypes, goal orientations and evaluations. They are also the distinctive ways an individual interprets experience, at what developmental psychologists describe as different stages of moral, ethical, and ego development and different stages of reflective judgement. "Although the transformation of meaning schemes is an everyday occurrence, the transformation of a meaning perspective is not" (Ibid., 1988, p. 226). Meaning perspectives involve criteria for making value judgements and for belief systems (Ibid., 1990). The centrality of meaning perspectives to adult learning is complemented by the qualitative research approach to this study. This approach seeks

to understand the ways in which people make sense of spinal cord injury within the context of their lives and the social reality they live in. Central to this type of investigation are the meanings that people attach to their actions and the strategies by which they act out their everyday lives. It would appear that the subjects in the study came to a clearer understanding of their meaning perspectives and were able to reflect on their utility and revise them in the light of the disability caused by the injury.

Mezirow (1990) provides examples of how meaning perspectives can be acquired through cultural assimilation, stereotyping in relation to roles and how they may also involve ways of understanding and using knowledge and ways of dealing with feelings about oneself. He suggests that familiar roles, such as, wife-husband, teacher-student, and employer-employee are predicated on established meaning perspectives familiar to everyone. In this way personal identity, self-concept and values are derived from prescribed social norms and conformity to stereotypical roles.

The individuals involved in this study, developed meaning perspectives through association with the majority group of able bodied in North American society. These meaning perspectives are derived from a society that places great value on youth, vigour, physical attractiveness, industriousness and independence. This same society places ongoing trust in the power of medicine to reverse the effects of disease and disability. In such a society there are powerful stigmas and little esteem associated with persons who lack these characteristics and the capacity for cure (Sim, 1990). Wright (1983) believes that one characteristic of the disabled as a minority group is to be perceived as

underprivileged, and according to the stereotype of one who has suffered a great misfortune, and whose life is consequently disturbed, distorted, and damaged. We early learn the concept of difference and the rejection of that which is different. This concept is reinforced by the literature of childhood which is full of ugly witches, hunchbacked gnomes and one-legged pirates. Advertisements and commercials eulogize the virtues of youth and beauty and suggest that beautiful people are the most successful and happy. These prevalent meaning perspectives were reflected in some of the subjects comments, such as:

Being physically attractive was very important to me and I just lost all sense of it after the accident.

I didn't want to be a burden to anyone so I went back to work, but it was way too soon. It was very stressful.

I was really athletic, my whole life revolved around working out, playing sports and the socializing that went with it.

I never had anything to do with someone in a wheelchair before. If I saw a person on the street I'd just try not to stare, but I used to feel so sorry for him, as if his life was sort of over. It's better nowadays, people are used to seeing guys get in and out of cars, doing things. Rick Hansen helped. But I think some people still look at quads as if they are invalid or something.

As a result of the experience of traumatic spinal cord injury these individuals became, virtually overnight, members of the minority of disabled in society. Initially their experience is controlled by their present meaning perspectives which are a reflection of how they experienced reality in the past. The results of this study would indicate these individuals' self-definitions of success are related to an emerging

ability, during the early months post-injury, to confront the inadequacy of their meaning perspectives under these radically altered conditions.

Health professionals also make meaning of the injury. It is a consensus of these meanings which governs the rehabilitation program philosophy, orientation and implementation. In some respects the health professionals meaning perspectives can be seen as representing the meaning perspectives held by the individuals before the injury. As a result a gap widens, despite the best intentions of individual health professionals, between the service offered by the rehabilitation program and the self-identified needs of the individuals with disability. The rehabilitation philosophy is unable to accomodate for the kinds of transformative changes in meaning perspectives these people are experiencing or to assist them in the learning process. If 'success' can be related to the ability of individuals to change and critically reflect on their meaning perspectives then these people are, in fact, least accomodated by this system based as it is on dysfunctional meaning perspectives.

Perspective taking, taking the perspective of others, "implies a conscious recognition of the difference between one's old viewpoint and the new one and a decision to appropriate the newer perspective as being of more value" (Mezirow, 1978, p. 105). This does not assume that the ability for perspective taking is universally developed, however, the capacity for perspective taking is essential to perspective transformation. As Taylor (1989) comments "one cannot transform a perspective easily if one is not aware of taking a perspective" (p. 146).

Learning to become aware involves a "process of reflecting back on prior learning to determine whether what we have learned is

justified under present circumstances" (Mezirow, 1990, p. 5). Douglas came to fully recognise his personal changes through working with newly injured individuals:

When I went back to [the rehabilitation centre] to do some counselling it was a marker for me. It was then I really noticed the difference between them and myself four years down the road. I kept seeing me, as I was then, in them and so see the difference in how far I'd come, not just physically but more mentally. I found I was able to look back to the things that had helped me along and translate some of that knowledge to them. But you know in the final analysis you have to go through it yourself.

Reflection is defined as "examination of the justification for one's beliefs, primarily to guide action and to reassess the efficacy of the strategies and procedures used in problem solving" (Mezirow, 1990, p. xvi). Mezirow equates reflectivity, self-consciousness and self-awareness and acknowledges their primary role in perspective transformation (Taylor, 1989, p. 147). In order to be even more specific the term critical self-reflection has been adopted. Mezirow (1990) considers critical self-reflection - "reassessing the way we have posed problems and reassessing our own orientation to perceiving, knowing, believing, feeling and acting" (p. 13) - to be by far the most significant learning experience in adulthood. Knowledge gained through self-reflective learning is appraisive rather than prescriptive or designative. The latter is more characteristic of the institutionalized approach of learning to cope with a disability.

An integral part of self-reflective learning is action. Malcolm is clear in his belief that what contributed to his learning process is:

Drawing on positive action. Success in any shape or form that makes us happy is part of the process of getting over the injury. I think the whole thing was a learning process of how the change has affected you and after a while nothing surprises you.

Action resulting from self-reflective learning is emancipatory. The learner is presented with an alternative way of interpreting feelings and patterns of action; the old meaning scheme or perspective is reorganized to incorporate new insights. The injury is initially viewed as alien to all previous experience, but over time, that experience becomes reorganised in order to incorporate it. As Ian said:

I'd lived the first 25 years of my life as a normal, able-bodied person. Didn't really ever think about disabled people or disability, wasn't part of my life. Then suddenly it happened to me. At first I kept thinking I'd get better, this will change, it can't be permanent. Well, I never got out of the wheelchair and eventually that fact sunk in. From then on I developed a different outlook on life. Very different than what I had before my accident. From then on I just sort of got on with it.

The individual comes to see reality more inclusively, to understand it more clearly, and to integrate the experience better (Mezirow, 1985a). The validity of these new insights or meaning perspectives can only be judged by the individual. Brian thought that, in the context of his own experience, "the accident was the hardest thing I'd ever have to cope with in my life." However, he recently experienced the death of his mother from cancer and he spoke of the insights he had gained through that loss:

It was devastating, far harder than coping with my accident. I realized that what I thought was the lowest point of my life, and the worst thing that could happen

to me, had faded into the past. The accident is only a part of the grand scheme of things somehow and life has a lot of others tricks, some good, some bad I guess, to play on me yet.

Coherence theory supports the notion of the validity of the reorganized meaning perspective. This theory holds that the more authentic a meaning perspective the more closely will the facts it addresses be related, and the more will it organise and unit them (Mezirow, 1985a).

The learning inherent in making meaning of the experience of spinal cord injury involves much more than mere changes in behavior or the acquisition of new skills and information. Indeed this learning process seems to overwhelm the individual at times, engaging the individuals' intellect and emotions in a manner that many of the subjects described as more profound than anything they had experienced before. Challenges and negations of previously constructed meaning schemes and perspectives are fraught with threat and strong emotion. The responses to spinal cord injury described by the subjects present a mixture of reflective, conscious, unconscious and instinctive action. Taylor (1989) provides a description of the effect new meaning perspectives can have on a person's life which could equally well describe the changes experienced by the subjects in this study.

According to Taylor:

New meaning perspectives lead to a new sense of identity and autonomy, self-confidence, a vision of new possibilities and alternatives for action, and the power to choose among them; all of which give people a sense of agency and responsibility for their lives and the power to take some measure of control over how they will live them. New perspectives give individuals a new conception not only of themselves but of their place in society. (1989, p.156-157)

Mezirow (1990) adds the proviso that "taking action on a new transformative insight can be blocked by external or internal constraints (or both), by situational and psychic factors, or simply by inadequate information or lack of skill to proceed" (p. 12). Ian described a situation at work, three years after his accident, which he recognised "set me back, had a real detrimental effect on our lives." A new foreman had been hired at the printing company who had:

A serious prejudice against the disabled and he just decided to get rid of me. He couldn't fire me openly so he set out to prove that I was incompetent. He made life really unpleasant for about a year. It was all I could do to summon the energy to deal with him. But all he proved in the end was that I was doing the job better than anyone. It really shook my self-confidence, a lot of stress I didn't need. People like that can have such a negative influence, who needs it eh? It's better now, he's backed right off. He didn't succeed with me but under different circumstances he might have ruined things for someone.

Perspective transformation has cognitive, affective and conative dimensions and refers to:

The process of becoming critically aware of how and why the structure of our psychocultural assumptions [meaning schemes and perspectives] has come to constrain the way in which we perceive the world, of reconstituting that structure in a way that allows us to be more inclusive and discriminating in our integration of experience and to act on these new understandings. (Mezirow, 1985a, p. 22)

Whilst the concepts of meaning schemes and perspectives are central to the process of learning through perspective transformation, and contribute significantly to our understanding of the learning process described by the subjects, their interrelationship with a number of

other concepts must also be explored as potentially informing the experience of spinal cord injury.

Mezirow's (1981) multidimensional conception of learning evolved from the work of Habermas who differentiated three generic categories relevant to what we interpret as knowledge. He suggested three distinct but interrelated learning domains - the technical, the practical and emancipatory. These cognitive interest areas are described as being grounded in different aspects of social existence: work, interaction and power (p. 4). Mezirow (1990) has further developed the concept of domains of learning and describes each in the following manner. The first domain is instrumental learning when we engage in task-oriented problem solving, that is, learning how to do something or how to perform (p. 7). This type of learning has as its basis a scientific or analytic approach. It is action oriented, the results of our action being evaluated and judged according to effective achievement of preset goals. Through instrumental action one seeks to control and manipulate the environment (Ibid., 1981, p. 4).

The first theme of rediscovering 'self' is associated with considerable stress which can be attributed to the sudden and radical physical changes resulting from the injury. A severe decline in self-concept is experienced. It is difficult for the individual to sustain a sense of 'self' in the face of severe loss of control over their physical functioning and environment, and if they are discounted in their previous social roles and relationships. This theme is concerned with the strategies employed by individuals to gain mastery over physical functioning and which enable them to progress beyond the issues of

survival. This involves learning new skills for survival and identifying and achieving new goals. Brian, still wonders at the shift in his thinking:

I never thought I'd enjoy wearing a suit and tie, I hated it before. I really enjoy it now. It's way better. Before the accident I was a bit on the wild side you could say. No real goals set or direction to my life. Since the accident life means way more. I get a real pleasure out of tackling new situations from the wheelchair. Every day is really an adventure.

This instrumental learning was facilitated, for the subjects, by the rehabilitation program. As Peter observed:

The rehab. centre was great, they tell you all the things you need to know at a time when you haven't a clue what's going on. But I never understood why they always seemed to have only one way to do things - their right way- when in actual fact it was only one of several ways someone like me could do it. But I only learnt that when I got home. There was alot of learning at that time. It was much easier once I understood that there was in fact no right way, just whatever suited me at the time and in a particular situation.

What is not taken into account by the rehabilitation program are the persons' past experiences of 'self.' The newly disabled person has not always been disabled. They bring to this 'dilemma' the accumulated experience of a life. Individuals who are newly injured are not, in my experience, treated in the rehabilitation setting as their nondisability-related adult characteristics would otherwise lead them to be treated. As health professionals our involvement and interventions begin at the moment of injury. The individual becomes defined by the injury and resulting disability. The emphasis of the rehabilitation program is consequently on the physical; the optimum restoration of bodily functioning. Within the sheltered environment of the rehabilitation setting the individual's history, lifestyle and social life is seen, by the

health professionals, as having little relevance. In contrast it is by the latter that the individual defines himself. The process they go through is the rehabilitation of the mind; restoration of their self concept and establishing a new identity. They must constantly struggle to regain a mastery over their own affairs that the able bodied are granted automatically. This struggle is reflected in the subjects' accounts as they spoke of the limitations imposed on them by the expectations, based on level of injury, of health professionals. Through the emerging new meaning perspective these individuals began to challenge the predictions made of the lives they would lead in the world outside the rehabilitation setting, and to determine their own learning priorities. William was "bound and determined" to do more with his life than seemed expected or likely:

I mean it was like I owed it to myself not to knuckle under this. That wasn't the way I did things before. Why should it change because of the accident?

Once the phase of not knowing what knowledge they need is past, each individual appears to engage on a unique self-directed learning process. Instructional resource people are varied according to each individual's need and frequently found serendipitously. Inevitably, as the impact of the physiological changes lessen through familiarity, new meanings are attributed to the experience of injury which assist the individual to alter their perception of reality in relation to disability, and incorporate it into their re-emerging self-concept. These new meaning perspectives enable the individual to make the shift from the 'tragedy' viewpoint to an acknowledgement of the reality of the disability and its effects on the quality of life. Stress, frustrations,

conflicts and limitations resulting from disability, are perceived from the 'tragedy' perspective as attributable to external sources, and as such, beyond personal control. Within a new meaning perspective the physical limitations imposed by disability are fully acknowledged and learning is directed at exploring and acquiring new ways of accomodating those limitations into a 'normal' life. It is obvious that these individuals develop a number of psychological and social mechanisms to assist their reintegration into society, and which enable them to cope with the behavior of others, and which are not addressed by the current educational model of rehabilitation.

The second domain is communicative learning. Not all learning involves learning to do. Communicative learning is grounded in social interaction and communication with others and is governed by consensual norms, judgements, propositions, beliefs, opinions, or feelings. The uniqueness of communicative learning stems from seeking the meaning and validity of the communication of others (Mezirow,1990, p. 8). Communicative learning is a case of:

Searching, often intuitively, for themes and metaphors by which to fit the unfamiliar into a meaning perspective, so that an interpretation in context becomes possible. (Ibid., p. 9)

This learning follows a process described as the "hermenuetic circle" in which "we continually move back and forth between the parts and the whole of that we seek to understand and between the event and our habits of expectation" (Ibid., p. 9). Through this type of learning new meaning schemes can be created which fit the components of the 'disorienting dilemma' better than our existing schemes and perspectives.

Meaning was attributed to the injury experience through the redefinition of disability; the second theme identified through the data. This was achieved by engaging the attitudes and stereotypes of disability held by themselves pre-injury and reflected by health professionals and society in general. In rethinking the relationship of disability with their daily lives, and with others, these individuals rejected the health professionals' devaluing attitudes towards their capabilities and potential. Not only did they reject them but they turned those expectations and attitudes into a challenge. The resulting action was directed at "proving them wrong." The subjects described their progress through the early years after their injury in such terms as "one step forward, two steps back" or "you win some, you lose some."

Influenced by the others' reactions to the disability their gradual rediscovery of 'self,' and integration of disability into their lives, proceeded in a pattern of retreat and advance. Positive influences were described as the support of family and old friends, who spanned the present injury experience connecting the past with the future and, in this way, represented the continuity of an individual's life. Friends reinforced the individual's self-concept by "treating me just like before," and recognising when "my old personality began to reassert itself." Tricia described the major influence her father had on her attitude to disability:

I could get away with whatever I liked with everyone else after the accident but not him. He treated me just like before. We'd always had this kind of relationship where he'd dare me to do something I thought I couldn't do. He approves of the way I'm handling this and that means alot.

Ian recognised how the quality of his relationship with Nairn has been enhanced as a result of his acceptance of the disability. Dirk learnt the hard way through a number of radical changes in his lifestyle and relationships. He feels his current contentment in his own home and a new relationship can be attributed to a combination of attaining a level of functional independence:

I finally feel that I'm back to who I was before. It's taken a few years. I'm really enjoying living on my own. My attitude to being in a chair is so different. I'm more secure, I've become stronger and yet more vulnerable somehow. I have a new relationship with an intelligent woman who doesn't particularly want to get married. It's not the sort of relationship I would have been in before my accident.

and to the new values he has adopted since his accident:

Where you come from is the heart and just that insight has been an enormous gain for me.

Negative influences included the loss of old friends "who couldn't handle seeing me like this," and persons' in position of power who presented obstacles to the achievement of goals, for example, Ian's foreman at work. As Ian said:

I had to work my butt off just to realign his thinking. I shouldn't have had to do that. People like him are a setback, influential in a negative way.

All the subjects spoke of the importance they placed in their association with others who shared the same injury in common. It was through a dialogue with their peers, particularly in the early years, that they were able to share relevant information, test out new attitudes, and formulate new ideas. Relationships with old friends and family were based on a sharing of common history and social context. These

new relationships were founded on the commonality of the injury experience. They were able to see beyond the visible disability to the inner 'self.' Each person engaged in their own unique process of establishing new meaning perspectives was able to recognize and appreciate a similar process in others. Douglas, in differentiating the learning he experienced within the rehabilitation program and after discharge, called the former "physical rehabilitation" and the latter "mental rehabilitation." In his opinion, one could not be achieved without the other. Health professionals, with their focus on the disability, were frequently effective in providing the former. However, in order to assist a person to achieve the goal of "mental rehabilitation" there must be an understanding of the meanings attributed to the injury by the person, and knowledge of that person's history and social context. The 'camaraderie' of the minority provided the basis of support from which new meaning perspectives could be tested and the stereotypes of the majority could be challenged.

In recent writing Mezirow (1990) has begun to stress the importance of the dialogic process which includes dialogue with self and dialogue with others, particularly the latter. Knowledge, then, becomes communicative, the result of consensually arrived at meanings obtained through the process of critical discourse in which contested meanings are confirmed or negated. The patient - expert professional approach of the rehabilitation programs does not facilitate such a process. Dialogue between peers, and newly injured and 'old hands,' while recognized by all the subjects as contributing significantly to their learning process, was left to occur on an ad hoc basis.

The third domain of learning is transformative learning. It is concerned with the development of self-knowledge through critical reflection. New meaning perspectives can be acquired but transformative learning is considered to have occurred only if insights are gained as to the significance and reasons underscoring them. Inherent in this type of learning is a freedom from institutional, libidinal, environmental forces which limit options and exert rational control over one's life (Mezirow, 1981, p. 5). It is characteristic of transformative learning to demand the total engagement of people as integrated whole beings. This integration is expressed in terms of the fusion of reflection and action (Taylor, 1989, p. 228).

The subjects appeared to have assimilated disability into the continuum of their lives and in so doing established a new identity based on the acknowledged reality of the disability. The subjects had become used to living with disability and unless faced with an unexpected barrier or a query from the curious, tended to be unaware of physical limitations. As Peter said:

The longer - it's going on four years now - that I live sitting down the less I think about it. It just becomes a part of you. Sure people stare but I don't notice mostly. I figure it's their problem not mine.

Ian contrasted this "life back to normal" approach with a person who was in the rehabilitation centre at the same time as him:

He never was able to come to grips with it, always wishing he could get a bit back [muscle function] so he could walk. He had loads going for him but he couldn't see it. Got into drugs and last I heard he'd died. A real waste!

Douglas, speaking from his experience as a counsellor, observed that:

In some ways I feel sorry for those guys who have low injuries. They are so much closer to normal it makes them really angry. Difficult to get out of that anger and get on with life. Whereas if your injury is like mine there's really no option but to think it through. Your brain becomes your best asset!

These comments place emphasis on the primacy of the mind in assigning meaning to the experience of injury, allowing them to reconstrue their world in ways that will accomodate disability

These examples of people who, according to Ian and Douglas, "didn't make it" illustrate the success-as-normalization approach to rehabilitation which leads individuals to conform to the society's definition of 'normal.' This definition represents an adherence to the old meaning perspectives. The learning process, in this case, is directed towards restoring physical function to as close to 'normal' as possible, and to appearing as 'normal' as possible. For persons' adopting this approach it is not the disability which limits their life chances but rather their compulsion to be what they are not - nondisabled. This approach involves the acceptance of others' definition of appropriate behavior and expectations of a person with disability.

The subjects in this study all defined themselves as 'successful' and in achieving this success have carved a new and uniquely individual path through the obstacles created by their own attitudes, and as a result of being a minority in society. This represents a major qualitative shift in their perception of the world around them, and of their relationship with that world, which suggests a radical change of consciousness or transformation. There is an underlying confidence in their own decision making powers and rationale for action which forms a base from which they can assert their viewpoint within the larger

context of society. In developing this new assertiveness they appear to have renegotiated definitions of 'normal.' Their new definition of 'normal' involved recognising and understanding their old meaning perspectives, critically reflecting on them and creating new ones more appropriate to the circumstances of disability. The subjects are able to see the disability from the perspective of others and work to actively influence and change their perspective. Douglas now feels that:

I am being judged on how I present, on how I contribute, not on the wheelchair. That's soon forgotten by most people mostly because I've forgotten about it. That realization helped me gain confidence and helped my communication with people.

Tricia laments the fact that people do not act normally around a person in a wheelchair, even when they have become acclimatized to the chair itself:

It's like they can't be honest, they keep up a phony friendliness. Before they probably wouldn't have passed the time of day with you. I wish they'd just say "I don't particularly like her." I get pretty good at spotting that attitude.

They acknowledge a self-consciousness and awareness of their interactions with the general public and people in positions of power. As Brian says:

People definitely look at you differently - not differently - look at you more. You attract more attention. It's hard to get used to at first. Now I quite enjoy the attention. I like to make a good impression you know!

Randy finds the "attention" more difficult to deal with but he says:

I'm learning to accept that its' [the attention] always going

to happen and that I have to use my personality to make them forget that I'm sitting down and they're standing up if you see what I mean.

This establishment of a new identity, and the ability to project for the edification of others, represents the profound nature of the learning process they describe in relation to the experience of spinal cord injury.

The themes of rediscovery of 'self,' redefining disability and establishing a new identity are artificially separated to expedite the presentation of the data. In reality they are all part and parcel of an ongoing learning process, occurring simultaneously and interwoven together. Transformative learning does not occur merely as a result of a disorienting dilemma, instrumental action, critical reflection and its resulting insights. It is rather a interweaving of all these components leading to a praxis. It is here that Mezirow (1990) suggests that "we enter into the conative dimension of transformative learning" (p. 355). The learner must make the decision - have the will - to act upon the new insights and meaning perspectives. This striving towards incorporation of the new meaning perspective into life is reflected in Malcolm's analysis of the problems some people encounter in trying to incorporate disability into their lives:

It's because they look at it [the experience of disability] through a screen they've developed in their own subconscious, their beliefs. If their beliefs don't let them remain open, to learn and to be ready for change then they're just going to proceed that much slower. It's like they're driving a car with the emergency brake on, they're getting somewhere but they're getting there very slowly.

Mezirow (1985c) describes three learning processes, based on the central concepts of meaning schemes and perspectives, which each operate in all three learning domains. The first is learning within

meaning schemes by differentiation and elaboration of knowledge. The second process involves the incorporation of the new meaning schemes which are "sufficiently consistent and compatible with existing meaning schemes to complement them within a prevailing or emerging meaning perspective" (p.11). The third process is learning through meaning transformation, that is, becoming aware of specific assumptions upon which a meaning scheme is based and through a reorganization or reframing of meaning achieving a new synthesis, a transformation (Ibid., pp.11-12). Malcolm relates "our programming," or old established meaning perspectives, to the ability to change and act on the change and, in so doing, indicates the reflective component of his experience:

I was like a computer with a blank disc and was programmed with a whole set of rules and beliefs, positive and negative stuff, by my parents. Then, when I grew up, I had to take that and blunder my way through life. It goes right back to our roots and we sort of unthinkingly accept it and keep perpetuating the same old stuff. Well, I had to do some major rethinking after the accident because none of that stuff was any help in this situation.

Reflection is considered an integral component of Mezirow's (1990) conception of learning and plays a part in all three learning domains of learning. In instrumental learning "we look back on content or procedural assumptions guiding the problem solving process to reassess the efficacy of the strategies and tactics used" (p. 7). In communicative learning reflection is directed towards achieving coherence. It takes the form of a critical assessment of the interpretation one has made of the process and the validity one has assigned to it. While all reflection implies an element of critique, transformative learning does not occur without the individual becoming

critically reflective. It is this that differentiates transformative learning from other types of learning. This is the term Mezirow (1990) reserves to refer to challenging the validity of presuppositions in prior learning. "It addresses the question of justification for the very premises on which problems are posed or defined in the first place" (p. 12).

Critical reflection transforms meaning perspectives through an assessment of *epistemic*, *sociocultural* and *psychic* distortions acquired through the uncritical acceptance of another's values (Ibid., p. 14). When based on mistaken premises in the first place, meaning perspectives become distorted. Epistemic distortions, according to Mezirow (1990), have to do with the belief held by an individual that every problem has a correct solution and the required knowledge is held by the right expert. This type of distortion is embedded in the medical model which has influenced rehabilitation philosophy and contributes to a generalized faith in modern medicine's capacity to cure all ills. It contributes to the attitude of health professionals and to the devaluation experienced by 'patients' with incurable conditions. Immediately after his accident William kept hoping for a miracle cure, and as he says it was some time before:

I basically figured that even if they did find a cure it wasn't going to be in time to help me. I've had to accept that I'll never again be like I was before.

Mezirow (1990) describes another example of this type of distortion as "reification," that is, seeing a phenomenon produced by social interaction as beyond human control, like the law and the government. A third type is based on description, for example, "using what psychologists describe as life stages as standards for judging a

particular individual's development" (p. 15). This aptly describes the adherence, by health professionals, to the stages model of adjustment to disability and their firmly entrenched expectations of levels of injury. In asserting themselves as individuals experiencing spinal cord injury in unique and different ways the subjects were forced, as part of their learning process, to challenge these distortions in others' perspectives. This recognition of the disparity between their newly created meaning perspectives and those of the health professionals was only possible once the subjects had consciously become aware of how their old meaning perspectives had shifted or been transformed.

Sociocultural distortions involve "taking for granted belief systems that pertain to power and social relationships, especially those currently prevailing and legitimizing and enforced by institutions" (Ibid., p.15). The commonly held belief is that health professionals, and in particular physicians, have the knowledge and expertise to effect a cure; that they know best, and following their instructions will ensure a person of continuing health. Accepting this type of distortion shifts the responsibility for health and well being onto another person and denies the role of the individual in assuming self-responsibility. Clearly the individuals in this study learn over time to assess this distortion and discard it as lacking utility in the context of their developing new meaning perspectives.

Psychological distortions have to do with the presuppositions based in childhood which result in past and present pressures and anxieties which impede action in adult life. These distortions are most effectively addressed by a therapeutic learning approach and counselling and are not directly addressed in this particular study.

However, grappling with these types of distortions is a uniquely adult characteristic. Issues of this nature do not go away simply because a person becomes disabled. Some of the subjects indicated that over time issues of this nature, integral to human development, occupied the forefront of their lives whilst the disability experience retreated to the background.

The traumatic severity of the disorienting dilemma is seen as increasing the probability of the occurrence of perspective transformation. Learning through perspective transformation can be painful because it "often involves a comprehensive reassessment of oneself and the very criteria that one has been using to make crucial value judgements about one's life" (Ibid., 1985a, p.24). Questioning the assumptions on which we act and exploring alternative ideas may be difficult particularly if our self-concept is highly invested in maintaining the old perspectives.

The traumatic nature of spinal cord injury appeared to leave these 'successful' subjects little alternative but to transcend the resulting disability through a transformative learning process. Acceptance of the disability was simply, in a way, acceptance of one self, which was, in turn, seen as a part of a much larger process. Things to which they had been previously attached, and which they considered significant, and were now interfered with by disability, were relinquished as no longer necessary to maintain an image of self. In familiarizing myself with the subjects responses to the injury, that is learning to see the world as they do, it became evident that each individual acted from the stable base of their previously acquired self concept. Although shaken initially by the injury their sense of self functioned as an anchor of stability in a

radically changed world. Through it they retain a sense of their own life history and individuality. Their self-concept in effect represents a continuum in their life at a time when the past and future are tenuously connected by a present filled with anxiety. It was from this base that individuals selectively chose to discard and retain old meaning perspectives and upon which new meaning perspectives were formulated. It is my opinion that these selective choices were made in order to keep the framework of the individual's self-concept relatively intact. In establishing a new identity an amalgamation needs to be made, of what proved relevant in the past, with what people learn will be of value and utility in the future.

Mezirow (1988) tends to place considerable emphasis on the negative aspects of psychological, social and cultural input to the structure of meaning:

Meaning schemes and perspectives are structures of largely unexamined presuppositions which often result in distorted views of reality: we get trapped by our own history. (p. 224)

Experience is seen as strengthening, extending, and refining structures of meaning by reinforcing our expectations about how things are supposed to be (Ibid., 1990, p. 4). This focus does not seem to take into account the possibility of positive aspects arising from an individuals' history. These individuals' had developed an experience base of capabilities and dispositions by which their everyday involvement with the world was governed, and by which they made sense of the world. It was these personality traits, which constituted their sense of self, and which they brought to the new situation of disability. As Larry said: "I

knew I was the same person but everything around me was so different." Peter knew that he had a lot to contribute to the new situation but as he commented:

When it first happens you get really down on yourself and can only see the predicament you're in. You have to convince yourself that you have the ability to deal with this situation just like you dealt with other things in your life before. It's just a matter of using what you got and rethinking a few things.

As Peter suggests an individuals' life experience and meaning perspectives may offer unique and creative possibilities in the transformative learning process.

Recently Mezirow (1990) has developed the notion of consensual validity which stresses the dialogue with others rather than with self:

Because we are all trapped by our own meaning perspectives, we can never really make interpretations of our experience free of bias. Consequently, our greatest assurance of objectivity comes from exposing an expressed idea to rational and reflective discourse. (p. 10)

Moving to a new perspective and sustaining the actions required is dependent on an association with others who share the new perspective and are willing to give support and reinforcement for the actions based on the new perspective (Taylor, 1989, p. 158). Consensus is sought, according to Mezirow, from those we feel are best informed, least biased, and most able to critically assess the evidence and arguments and arrive at the best judgement in conjunction with the individual. Within the discussion of consensus the individual process of personal dialogue and reflection, as an act of consciousness, is down-played.

Essentially the subjects in this study describe a solitary process of learning. Contacts with their peers or resource people, particularly after discharge when it would have been most useful, occurred mostly by luck and chance rather than as a planned strategy. The subjects all considered input from others, who shared the commonality of injury, was valuable but this type of dialogue was not consistently available for all the subjects. As Dirk said:

The first years, I think, would have been so much easier if I could have checked in with others who knew the experience, if I'd had someone to talk with who knew what it all meant.

Brian admits that:

You have to work things out for yourself but you need suggestions, someone to come up with motivation or ideas when you get stuck. I was lucky I could fall back on Greg but most people didn't have someone like him. It made it way more easy for me.

Health professionals' who might be considered to be the 'best informed and least biased,' potentially have the opportunity to act as facilitator, catalyst and supporter in the learner's process of transformative learning. Some individual health professionals' were recognized and acknowledged by the subjects as fulfilling this education role within the rehabilitation setting, but as a group, their effectiveness is blocked by their own agendas and assumptions of knowledge.

The ongoing process described by the subjects is an intensely personal one. As Douglas said "It's a matter of thinking it all out for yourself right from the start." Larry feels his old personality helps him:

Even ten years ago I was always to do things different ways. Now it's a case of believing that. I'll think of a way to do something, check it out, but none of us are right all the time

nor will we ever be. So I'm always ready to accept another opinion, try it another way but you've got to make the moves yourself. None of us stop learning until they close the door on us!

Inherent in these accounts is a reliance on their sense of self and an emphasis on the centrality of self-help and self-exploration. This emphasis is not reflected in Mezirow's move towards validation of meaning through critical discourse. The self-confidence needed for perspective transformation seems to be gained through reliance on a concept of self developed prior to the injury, an increased sense of competency, and a supportive social climate and peer group. The education required to facilitate transformative learning cannot be defined by a simplistic preoccupation with fostering direct behavior change (Mezirow, 1978). If the learning process engaged in by individuals' learning to live with sudden disability is recognized as transformative, then we need to develop ways of acknowledging the centrality of the individuals' experience, and identifying meaning perspectives which facilitate, reinforce and inhibit the transformative process.

In conclusion, Mezirow (1990) has brought together these various concepts in the following explanation of transformative learning:

Transformative learning involves a particular function of reflection: reassessing the presuppositions on which our beliefs are based and acting on insights derived from the transformed meaning perspective that results from such reassessments. This learning may occur in the domains of either instrumental or communicative learning. It may involve correcting distorted assumptions - epistemic, sociocultural, or psychic - from prior learning. (p. 18)

In this chapter the subjects' conceptions of traumatic spinal cord injury, as identified through analysis of the data, have been revisited and described as a complex and personal learning process by which disability is assimilated into the continuum of their lives. This description lends itself to interpreting disability as a growth experience; an event to be transcended and from which an individual moves on. Transformation may occur as a result of the sudden onset of the disability 'dilemma.' Mezirow's theory of transformative learning is considered as a possible alternative, or adjunct to, the educational model of rehabilitation provision.

Transformative learning requires that the individual understand the nature and the extent of the limitations, the probability of permanence, and the realities of dealing with society without recrimination or an overwhelming sense of loss. This understanding is achieved by questioning old meaning perspectives and creating new ones. Disability, viewed from the new meaning perspectives, is seen as an inconvenience to be mastered and has neutral valence. However, perspective transformation can only occur when the individual can critically reflect on the experience of disability, shape and develop reality in relationship to it, and use the new vision of reality as a means to move towards further transformative learning. In the final chapter the findings of this descriptive study on how people conceptualize the experience of spinal cord injury will be compared with the existing literature. The research question will be addressed in relationship to Mezirow's theory of transformative learning. Implications of the findings and the theory of transformative learning for the educational model of rehabilitation provision will be discussed.

Chapter Six: CONCLUSIONS AND IMPLICATIONS

This study explored how people conceptualized their experience of traumatic spinal cord injury and the resulting disability using an interpretive and descriptive approach to gather and analyze the data. The focus of this research was to more fully understand the meanings attributed to the experience of traumatic spinal cord injury revealed in the language used by the subjects in describing the experience. The data collection method chosen was semi-structured interviews. Interviews were conducted with subjects who defined themselves as "successfully rehabilitated."

The purpose of this chapter is to integrate and compare the findings of this qualitative study to a theory of transformative learning and the existing rehabilitation literature. The implications of this study to the provision of rehabilitation programs within formalized settings by health professionals, such as, physiotherapy and occupational therapy, will be discussed.

Summary of Study Findings

As researcher I chose the descriptor "rehabilitated" and used it during the early stages of the study. It became apparent that the subjects and I defined rehabilitation in differing ways. The term rehabilitation was confined in its use, by the subjects, to the formal rehabilitation program provided within the institutionalized setting, and was not associated with their experience after discharge. Whereas I used the term 'rehabilitation' to describe a lengthier process of 'adjustment,' or 'coping' with disability occurring after discharge from

the formal rehabilitation program. The subjects' definition of rehabilitation was adopted for the purpose of this study and used only to denote the rehabilitation program provided by health professionals.

The rehabilitation program, from the subjects' perspective, is characterized in a number of ways. This program was seen as providing instrumental instruction based on the expectations of level of injury and independence as ultimate outcome. The injury was seen as the focus of attention by health professionals providing instruction and care. The attitudes and expectations held by health professionals were perceived as unnecessarily limiting and not related to life in the 'real world' after discharge from the institutional setting. Through the rehabilitation program individuals gained essential knowledge and skills by which they could regain a sense of control over their physical functioning. Particularly for those individuals with high levels of injury this control was related to being able to 'tune into their bodies' and instruct others in their care.

It became evident that learning occurred, during the first year after the injury, almost exclusively within a hospital or rehabilitation centre. Through these institutions, family and society the messages of injury as 'tragedy' and that individuals who sustain injury are less than they used to be, are subtly communicated. The instructional program is perceived as exhorting the person to strive to be 'normal.' The planning and implementation of rehabilitation programs appears to be driven by a response to the injury and its physical consequences, and a conceptualization of injury as 'tragedy.' This notion is supported by both my own experience as a physiotherapist and the subjects' descriptions

of their experience of the rehabilitation service they were provided following injury.

The findings of this study, that is, the commonalities of meanings attributed to the injury by the subjects were found to be the reverse of those conceptualizations of injury and disability held by health professionals. The subjects characterized the injury as a significant life event which caused considerable disruption of their present lives. The individual person and the continuity of 'self' were seen as being related to the context of their whole life and of primary importance in the rehabilitation process. In contrast the health professionals' emphasis and apparent conceptualization of the rehabilitation intervention is the injury. Expectations, held by health professionals, of future capabilities and quality of life as communicated to these subjects, were derived from that consideration.

The meanings attributed to the injury were revealed through analysis of the data and were grouped into three thematic categories; rediscovery of self, redefining disability and establishing a new identity. These themes, whilst representing commonalities, revealed the complex and multidimensional nature of each individual's experience. The emphases placed on the meanings identified, and combinations of strategies used to accommodate to disability following spinal cord injury, were uniquely individual. The themes have been presented in a chronological manner. In presenting the themes in this way it was not my intention to suggest that, in the reality of the individuals' experience, they unfolded in a chronological fashion. Within that reality these meanings, and the strategies employed, are interwoven and evolved, over time, in relationship to each other. In attempting to gain a

fuller understanding of the experience of sudden traumatic injury and its' consequences, it became evident that the subjects were engaged in a transformative learning process that has not been addressed in the literature or in the development of the education model of health care delivery.

The injuries these people sustained caused radical changes to the physical image of the person or the 'external' self. These changes were associated with feelings of fear, inadequacy and loss of control. All the subjects consistently maintained that they were the same person as before the injury. This 'internal' concept of self represented their accumulated life history and experience but they did not feel that this was recognized by health professionals, or others around them, who were predominantly influenced by visible physical changes. The paradox strongly stated is "how can two views of self be held, that of being disabled, and that of being normal?" Efforts to close this experiential split initially directed the learning process.

The theme of rediscovering self was concerned with gaining control over the physical ramifications of the injury. The rehabilitation program provided important information about altered physiological functioning, and taught the skills essential for survival following the injury, and for sustaining health in the future. The ensuing knowledge base resulted in a revived sense of self. From this base the stereotypes and attitudes of others were challenged. "Proving them wrong," and asserting one's view of the future, further increased self confidence and enabled the individuals to carve out their own definitions of 'normal' and 'disability.'

Society's definition of normal focuses on the relationship of the able-bodied to the environment. Disability denotes a different relationship. It is hard for society to accept difference without somehow ranking it as inferior, deficient or dysfunctional. These individuals appeared to have acknowledged the realities of physical disability and redefined the relationship of disability with society. "Getting back to normal" meant achieving the goal of flexible, mature participation in the mainstream of society. Resumption of normalcy was associated with creating healthy interdependent relationships with others, recognising the many possible options and values open to them, and developing the ability to choose and experience the most fulfilling ones.

Spinal cord injury is also an assault on the individuals' sense of personal identity. A sense of identity involves a complex combination of the individual's self-concept, history and roles in relation to significant others and to society. Immediately following spinal cord injury a whole series of "I am's" are no longer relevant and a loss of identity is experienced. The learning process involved letting go of some "I am's" and developing others about which the person could feel good.

Rehabilitation programs were associated, by the subjects, with 'physical' as contrasted with 'mental' rehabilitation. The two seemed distinct and separate in the subjects' minds. 'Mental' rehabilitation was seen as occurring, primarily after discharge from the rehabilitation facility, through their efforts to reassert their own sense of self over the changed circumstances of disability. The subjects perceived "success" in terms of their psychological development, "maturing," "growing up" "my attitude to life" rather than in terms of physical functioning and ability. These two types of learning, 'physical' and 'mental' appeared in general,

as separate entities in the treatment of disability. The latter type of learning involved, not only, the application of self-care knowledge and skills to survival in the world outside of the facility, but also the development of new social roles, and skills in communication, administrative and economic survival. 'Mental' rehabilitation seemed to occur largely in isolation, without professional support, and was reinforced by the experience of disability in the context of an individual's lifestyle and social environment.

The subjects considered the mind to be one of the greatest assets in achieving "success." While the contribution of the rehabilitation instruction, and particularly that of individual health professionals, was acknowledged, "success" was attributed more to their own personality traits, their past experiences, their relationship with others and the new priorities they set for themselves. The title of Bruner's (1986) book Actual Minds, Possible Worlds encapsulates the essence of these individuals' collective experience. These individuals can be seen to have "actual minds" and they create "possible worlds" which are quite different and divergent from the "worlds" that non-disabled people envisage for them.

Central to this creation of "possible worlds" is the continuity of their sense of self-concept. For these subjects who were viewing the injury experience from a distance of five years, the disability had been substantially assimilated into their lives. The injury temporarily disrupted their lives and undermined their sense of self and identity. Most felt they were "back on track" or close to it, and that life was continuing along similar lines to before the injury. The learning which resulted from the injury experience was described as "unexpected,"

"sudden," "unlike anything they had experienced before," but also part of a process, sometimes related to disability sometimes not, that they could see continuing throughout their lives.

This view of disability integrated into a life continuum, and assimilated as a part of a larger lifelong learning process, is in direct contrast to the prevailing view of disability as a 'tragedy' which causes devastating and irrevocable changes to a person's life. The existence of these contrasting views of disability and its impact on quality of life may offer a mechanism by which the inadequacies of the rehabilitation program can be explained. Health professionals appear to attribute meaning to spinal cord injury and the resulting disability which are based on society's concept of normal. Successful rehabilitation is evaluated in terms of the individual's approximation to normality. This emphasis on normalization denies the varied self-definitions of success suggested by the subjects' descriptions of their experiences. Their evaluation of success was based on a dynamic and even transformational process which emphasizes the potential of each individual to create and embrace new opportunities and to manage their own lives.

The process of learning to live with disability has been variously described by health professionals using the terminology of 'adjustment,' 'coping,' 'adaptation' and 'rehabilitation.' The intensely personal learning process described by the subjects has lead me to question the use of this terminology. This inadequacy can be illustrated by considering the word 'rehabilitate.' The dictionary (Webster's, 1988) defines to rehabilitate as "to put back in good condition, to restore to a normal or optimum state of health or constructive activity." The concept of

restoration to a previous state is simply not possible for many people following spinal cord injury. This concept denies the validity and value of the disability experience as a significant life event which is assimilated into an individual's life, and which may trigger transformative changes and psychological growth. The subjects did not present the learning process as unerringly positive, nor were they unrealistic about the limitations imposed by the disability. However it seemed that, over time, these individuals did perceive the disability as one factor amongst many which impacted on their lives and influenced their continuing development as a person.

A Theory of Transformative Learning

In the presentation of the data it was noted that the subjects' descriptions of their experience constituted a remarkable learning process which was not adequately addressed, or informed by, the current educational model of rehabilitation or by the reality of rehabilitation practice. A transformative theory of adult learning as proposed by Mezirow, in which construing meaning is of central importance, would appear to offer an alternative theoretical framework to explain the experience described by the subjects. For Mezirow (1990) learning is not a desirable outcome or goal; it is the activity of making an interpretation that subsequently guides decision and action. Interpretations are made based on the grounds of personal reality and experience and in the context of existing meaning schemes and perspectives. Spinal cord injury acts as a 'disorienting dilemma' which propels the individual into a conscious discovery and experience of a new vision of reality. This shift of consciousness requires that old

meaning perspectives be brought into consciousness, examined critically and transformed.

Mezirow through his explanation of perspective transformation as a major component of adult learning supports the idea that the development of consciousness is an essential element in the development of self concept and identity. This conception of consciousness recognizes the power of reflection, that is, the ability to consciously turn back on experience. Reflection is the uniquely human component of consciousness which fuels human progress and learning (Taylor, 1988, p. 188). Mezirow (1990) emphasizes the importance of reflectivity in human development and defines consciousness in terms of a finely graduated set of levels of reflectivity, crowned by critical reflectivity.

According to this theory, each individual brings to a particular moment or event a unique construction of reality which is not static but dynamic, which can be transformed and changed to become part of the individual's future. This is strongly related to Bruner's (1986) discussion of how multiple realities or possible worlds are created, individually and collectively within the context of culture. Mezirow sees personal reality as embedded in socio-cultural-historical reality. A 'disorienting dilemma' creates the need to bring these realities into conscious awareness and critically examine and transform them. In this way, a personal vision of reality is construed rather than merely a response being made in reaction to external factors, such as the consequences of a traumatic injury. The personal process of reality construction results from the creation of a personal meaning system which is subject to revision, change and transformation. Mezirow suggests that the process

of change or transformation in personal meaning systems is a distinct form of adult learning.

According to Mezirow (1990) this type of learning is grounded in the very nature of human communication. Through dialogue with others, individuals can assess new perspectives and build upon or discard them. As individuals move progressively from perspective to perspective they continually reinterpret and reconstruct the reality of their past and present. They may incorporate older meaning perspectives into their present one, but they can never return to the old ones in their original form (Taylor, 1988, p. 152).

The people who participated in this study described a dynamic and complex learning process which they were conscious of being embarked upon. The 'disorienting dilemma' of spinal cord injury propelled them into a learning process which they describe as occurring as a series of gradual transitions rather than a sudden insight. The 'dilemma' created a number of troubling contradictions which demanded attention. These have been described as the 'experiential split' experienced in the early phases after injury, the loss of roles and goals, and reconciling conflicting concepts of normality. Mezirow suggests that only by confronting reality can old meaning perspectives be questioned and evaluated as inadequate in the face of the changed circumstances. In rediscovering self the subjects were forced to confront, at a personal and social level, the reality of disability, its' implications and consequences. Old meaning perspectives pertaining to their roles, attitudes towards disability and the course of their future are called into question. Their relationship with reality at this time is a transactional one, a combination of action and reflection. Action is

directed towards acquiring the skills to survive the consequences of injury and reflection is directed towards challenging the attitudes of others and stereotypes of society, and developing new goals and priorities. Building a new framework of experience and testing out new meaning perspectives occurs in a cyclical fashion or advance and retreat pattern.

These shifts of consciousness are reinforced by dialogue with others who have sustained the same injury, and close family and friends, who see the individual beyond disability. As a result of these shifts of consciousness the subjects were able to redefine disability and establish new identities. New meaning perspectives having proved effective under the new circumstances and being reinforced by "old hands," lead to a willingness to generate new options and entertain new values. The subjects spoke of the first two years after injury as "like doing hard time" and associated those years with an enormous expenditure of effort and personal struggle. The reality of the disability and the inherent losses had to be confronted, the attitudes and expectations of others had to be challenged and their own isolation dealt with. Through the process the subjects created new 'possible worlds,' triggered initially by the injury but sustained by the congruence of the 'possible worlds' with a continuing sense of self.

The element of time was considered to be important by all the subjects. The greatest learning was perceived as occurring after discharge from the rehabilitation setting and 4-5 years after the injury this learning was described as 'an adventure,' 'being back on track,' 'life means so much more' and 'getting purpose back again.' New meaning perspectives achieved by taking risks, and often with difficulty, once

established lead to a sense of confidence, accomplishment and even exhilaration. The insights gained were seen to have influenced every aspect of life and disability assumed a neutral valence. The learning was interpreted in the context of their whole life and, as such, connected past, present, and future. The 'rehabilitation process,' related to the injury, became only a small part of the whole picture: The rest of the picture being more truly described as a process of personal development through perspective transformation.

Comparison of Findings with Rehabilitation Literature

Rehabilitation philosophy and practice has been dominated by the medical model approach to disability management and research. The medical model has as its goal the physical restoration of disability. It is based on the premise that when a person has a disability, something can be done to reduce or eliminate the effects of disability, and that when physical restoration is successful, social and employment restoration will automatically follow (DeLoach & Greer, 1981, Lorig & Laurin, 1985, and Trisechmann, 1988). The findings of this study suggest that the primary imperative following injury is the assimilation of disability into the individual's life. To achieve this goal the subjects brought personal traits and life experience to bear on the new situation of injury. It is becoming clearer that it is the equally profound psychosocial process, by which a person learns to live and compete in a world designed, and dominated by able bodied persons which need to be identified and explored. Research, however, into the psychological and social aspects of spinal cord injury has focused primarily on identifying specific personality traits that have characterized the

promising candidates for rehabilitation. The emphasis has been on the assets and liabilities of the person that lead to success or failure.

The educational model of rehabilitation provision emphasizes a holistic approach to rehabilitation, in which people with disabilities are active and equal participants in the process. This model does address the issues raised when physical restoration is not the primary goal of rehabilitation. The goal of rehabilitation according to this model becomes the facilitation of independent living, that is, the provision of the information individuals require to gain a full understanding of their altered physiological functioning, to guide others in their effective care, and to make informed choices by which they can manage and control their own lives. Rehabilitation practice, however, continues to be dogged by the "aura of paternalism" (Phillips, 1985) inherent in the medical model of rehabilitation and which is difficult to reverse. Treatment is provided within a formalized, structured setting in which the 'patients' are often totally separated from their own social context environment.

Within these models health professionals have traditionally been assigned as the experts with regard to identifying the goals or outcomes of rehabilitation, establishing the skills and knowledge required to achieve those goals, and evaluation of successful rehabilitation. In formulating the rehabilitation package the individual is essentially assigned a passive role. Health professionals begin their interventions at the injury point of a person's life. These instructional interventions are focused almost entirely on the management of the physical ramifications of disability. As a result of this focus, health professionals are not particularly interested in, or see the relevance of, understanding the person as he was before. The person is therefore defined, by them,

in terms of his injury level and physical deficits rather than in relation to his historical and social context. For the individual the question becomes "how can the disability be assimilated into an existing life?" rather than the health professionals' question "how can the individual adjust themselves and their lives to disability?"

There is an acknowledged paucity of direct information concerning the feelings, wishes and self-definitions of persons with disability which studies such as this are attempting to rectify. Recent studies (Cogswell, 1984, Creek, 1987, and Oliver et al., 1988) have emphasized the need to expand investigations of the responses to spinal cord injury beyond individual personality traits and physical functioning to incorporate a wider set of factors, such as, personal, social, economic, and environmental. Despite these attempts to broaden the scope of practice and to operationalize an educational model, the 'personal tragedy' view of spinal cord injury and the stage theories of adjustment continue to pervade the health professional viewpoint. From this perspective spinal cord injury is seen as causing huge and permanent changes in a person's life, and individuals fall into either the 'supercripple' category in which they are judged to be successfully rehabilitated, or those who succumb to the tragedy and who suffer less than fulfilling lives. Individual responses which do not coincide with these perspectives, any questioning or rebellion against the goals and methods of the rehabilitation service, are frequently interpreted as an inability to adjust to the injury.

The ideology of rehabilitation exerts 'patients' to work hard at attempting to fulfill ordinary standards and strive to appear 'normal,' while at the same time teaching them to appear different. The

underlying principle of normalization upon which this assumption is based focuses on minimizing the stigma of disability which activates society's labelling as inferior or devalued rather than on changing the definition of normal and the perceptions of society.

The assumptions expressed in the rehabilitation literature, and embodied in rehabilitation practice, are called into question by the findings of this study and which are supported by the major components of Mezirow's theory of transformative learning. The premise upon which this theory is based is that learning is a broader phenomenon, more inclusive of human experience, than is generally acknowledged in traditional education settings. This theory was selected on the basis of its' ability to speak directly to the experiences described by the subjects. Central to this theory is the power of the mind. Learning is seen as occurring when the individual becomes consciously aware of their meaning perspectives, or world view, with which they guide their lives, and the possibilities and limits that these entail. Becoming aware is the first step towards a sense of control and personal choice in their lives and requires learners to be able to distance themselves or stand back from their experience. By critically reflecting back on their experience they can see themselves and their experience more clearly. This theory supports the individual interpretation and unique qualities of the experience. Interpretation of new experience is perceived as being grounded in the learner's previously constructed world and their established meaning perspectives.

The subjects appeared to be actively engaged in constructing a new, but personally congruent, reality. Not only had they defined themselves as 'successful' but they also seem to have redefined the

term 'normal,' not in terms of the visible disability, but in terms of personal involvement and contribution to family, friends and society. New options were formulated by which purpose could be reintroduced into life and new values were explored based on the redefinition of the idea of relationships and independence. The issues of stigma which revolve around the 'difference' resulting from the public image of disability were deemed as 'their problem not mine.'

The type of learning the subjects described had elements that could not be accounted for by usual approaches to learning and which were not incorporated or acknowledged within the rehabilitation system. The experiential data provided an opportunity to examine this learning from a personal point of view. Integral to this viewpoint was that the learning triggered by the injury event had a degree of consistency with their pre-injury experience and that as a result of the learning they were 'back on track.'

The disability was assimilated into the context of a whole life. Instead of being experienced as a physical trait the disability became a set of physical characteristics which influenced function. In time the disability was subsumed by developmental experiences which were not unlike the developmental experiences of other adults. The experience was perceived as presenting unexpected psychological and spiritual learning opportunities. The learning triggered by the injury was seen in the context of a lifelong learning process rather than a clearly defined moment of learning or change. Mezirow (1981) claims that transformational learning, that is, a move towards new perspectives may be "explained as a quest for meaning by which to better understand ourselves and to anticipate events" (p. 7). The new

orientation to life "as part of a journey towards maturity is not an easy one" (Ibid., 1978, P. 105). The inclusion of consciousness and critical reflectivity into a theory of learning shifts the focus of learning from skills acquisition and a stages model to a continual lifelong process.

Moving through this process, becoming consciously aware, demands that people enter into relationship with others through dialogue to enable them to confront and understand their common reality. Transformation becomes a gradual process of gathering new meanings through confronting the unknown (Ibid., 1981). Partial insights direct the way individuals collect additional information, and this is compared and related to the experiences of others through critical discourse. In redefining disability the subjects all emphasized the significance of their dialogue with their peer group and the importance of sharing knowledge and expertise with each other.

Limitations of The Study

This exploratory study involved a small group of subjects self-defined as 'successfully rehabilitated.' These diverse self-definitions of success were not consistent with the traditional goals of rehabilitation, or with the notions of success for people with disabilities held by health professionals or society. Success meant a different thing to each subject. The centrality of this notion of 'success' to each individual's learning process and identity became apparent to me as the research unfolded. More attention may need to be given to formulating interview questions which reflect the diversity of these self-definitions.

The findings of this study are specific to the subjects and as such may not reflect or describe the experience of a larger population of

people with spinal cord injury. This study, in common with others reviewed in the literature, did not differentiate between people with high and lower levels of injuries in analyzing the data. The findings suggest that persons with higher levels of injury require longer periods of time in which to make transformative meanings of their experience and to assimilate disability into their lives. The accounts of these individuals seemed particularly rich in detail compared to the subjects with lower levels of injury. It seemed that they were more conscious and reflective of their experience. One possible explanation is that the level of injury demands a different type of response. This could not be explored adequately given the delimitations of the study. In future studies it may be useful to explore the differences between the responses of persons with paraplegia and quadriplegia.

Mezirow's theory of transformative learning is very comprehensive and rich in detail. It is not, however, presented by Mezirow as a thoroughly integrated and coherent whole. The theory continues to evolve and as such may be confusing to readers in its present state. The theory in its present form does, however, encourage further exploration of ideas leading towards viewing learning following traumatic injury as a transformative process.

Implications for Rehabilitation Practice

The findings of this study, the qualitative research method used and the introduction of a theory of transformative learning, have certain implications for the rehabilitation practice of health professionals. Attempts are being made to operationalize educational models of rehabilitation service such as proposed by Trieschmann

(1988). Her model outlines three major categories of activities or behaviors - survival activities, harmonious living and productivity - which could serve as the basis for planning and implementing rehabilitation programs. These categories are defined in predominantly behavioral terms but can be seen to share commonalities with the themes of rediscovering self, redefining disability and establishing a new identity. By expanding these behavioral outcomes to incorporate the meanings attributed to the experience by those individuals who have sustained spinal cord injury, health professionals would gain a greater understanding of the complexity of the learning process involved.

Because of the lack of comprehensive follow up programs, and the dearth of studies ascertaining how persons with spinal cord injury perceive the rehabilitation instruction they received, health professionals have been able to deceive themselves that the traditional inpatient rehabilitation program constitutes the most effective and optimal method of service delivery for persons with disability. It is short sighted to view rehabilitation just in terms of the inpatient experience, as though to be rehabilitated is a finite quality, which can be achieved entirely within the rarified environment of the rehabilitation setting. The findings of this study suggest that the injury event is assimilated into a lifelong learning process and that within this continuum disability becomes subsumed by other demands of adult life. I have become increasingly aware, through contact with the subjects, that health professionals sustain an unreal view of what constitutes living with disability. Most health professionals are personally and socially isolated from the people we serve. Whilst the 'experts' are

willing, and see the value of, sharing their expertise with both health professionals and newly injured people there has been little effort to date to capitalize on their expertise and knowledge.

The subjects' descriptions of their experience mirror and confirm what some health professionals have observed in their clinical practice. Giving credence to people's interpretation of the experience of injury and disability by rigorous and consistent research would assist health professionals to recognise their preconceptions about disability and the role of rehabilitation programs. Faced with different ways of perceiving the reality of disability we would not be able to continue to deceive ourselves that we are the 'experts,' and that current rehabilitation practice is the best and effective way to prepare people for living with disability. Listening to the real 'experts' will, I think, dispel the malignant myth prevalent amongst health professionals and the able-bodied that severe disability invariably compromises the quality of an individuals' life.

Introduction of a theory of transformative learning would provide a mechanism by which the experience of spinal cord injury as described by individuals could be explained and disability reconceptualized by health professionals. This theory would add breadth and depth to the scope of the proposed educational model of rehabilitation service provision. Implementation of such an expanded model would lend itself to a more client centred approach. Transformative learning theory acknowledges, and lends credibility to, the meanings attributed to the experience, and the interpretations of disability made by individuals, who have sustained a spinal cord injury. It would assist health professionals to identify their own meaning

perspectives and assumptions about disability and the premises which have governed rehabilitation practice to date.

The findings of this study appear to suggest that the target of an education program may, in fact, not be those individuals with spinal cord injury but health care professionals. In facilitating a clearer appreciation, on the part of health professionals, of the transformational and individual nature of the experience of spinal cord injury the gap, identified between what is offered and what is deemed relevant in the 'real world' of each individual, might be narrowed. It is not that the actual instructional content of the rehabilitation programs is inadequate, but rather that those interventions must be tailored to capitalize on the individuals' life experience and to suit particular needs. Not everyone will be as 'successful' as the subjects who participated in this study but learning from their experience may assist us to develop a more relevant program in which content and instruction are grounded in the individuals' history, lifestyle and social context. Future research employing rigorous qualitative approaches may answer questions arising from this study, such as, what does success in learning to live with disability mean to persons sustaining traumatic injury, how are these definitions of success inconsistent with the traditional goals of rehabilitation programs, what attitudes do health professionals hold about disability, and disability-appropriate behaviors, which influence their clinical practice?

As Trieschmann (1988) says the key to a change in the provision of rehabilitation programs is the attitude and behaviour of the health professionals who interact with persons with disability. Many health professionals working within the system recognise its inadequacies but

have lacked research evidence and theoretical alternatives upon which to base a change of practice. By focusing research endeavours on understanding the diversity of responses to injury, health professionals may gain valuable information by which to broaden our own perceptions of disability, and facilitate a more flexible approach to the provision of instructional events. Application of qualitative research methods provides us with the opportunity to establish a broad, integrative knowledge base from which to plan rehabilitation programs, and which acknowledges the subjective experiences of those people who have sustained a spinal cord injury.

In summary in this study I used a descriptive and interpretive research approach to ascertain how people conceptualize the experience of spinal cord injury. Three themes, rediscovery of self, redefining disability and establishing a new identity, by which the subjects appeared to make meaning of their experience, emerged from an analysis of the data. It became apparent that these individuals were engaged upon a complex learning process. Important in this process was the individual's perception of the continuity of self, and the relevance of learning to their own social and personal context. The process was strongly influenced by psychological and contextual components and was seen to extend, and in some cases, to begin after discharge from the rehabilitation facility. The changes in perspective described by the subjects were seen to resemble perspective transformation, a central concept in Mezirow's theory of transformative learning. This theory was presented and discussed in relation to the study data as a possible alternative approach to the interpretation of individual experiences of

spinal cord injury, and on which future rehabilitation program interventions might be based.

If, as health professionals, we could begin to see traumatic injury and the resulting disability as a significant event to be absorbed into the continuum of a person's life, rather than 'tragedy' wreaking permanent havoc in a person's life, then we could begin to narrow the gap between the instruction we provide and the needs identified by individuals as being relevant for their situation. The key, it seems, is perceiving disability as a part of the picture of a person's life not the whole. Samuel Butler (cited in Antonovsky, 1979) captured the essence of the whole when he said:

All our lives long, everyday and every hour, we are engaged in the process of accommodating our changed and unchanged selves to changed and unchanged surroundings; living, in fact, is nothing else than this process of accommodation; when we fail in it a little we are stupid; when we fail flagrantly we are mad, when we suspend it temporarily we sleep, when we give up the attempt altogether, we die.

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APPENDIX A

Subject Profiles

TRICIA

Date of interview: September 20, 1990
Year of injury: 1986
Cause of injury: Motor vehicle accident, driver of car, hit a horse loose on the road.
Level of injury: C8 quadriplegia
Age
(at time of interview): 21 years
Living situation: Independent, living alone in cooperative apartment.
Mobility/
Transportation: Manual wheelchair, drives own van.
Interests: Attending community college doing university prerequisite courses.
 Close supportive family living in Interior B.C.

WILLIAM

Date of interview: May 31, 1990
Year of injury: 1986
Cause of injury: Run off the road by a truck while competing in a Trans-America bicycle race
Level of injury: T6 paraplegia
Age
(at time of interview): 39 years
Living situation: Lives in the house he owned pre-injury. Inside elevator and ramps added since injury. In partnership with a woman he met since his injury.
Mobility/
Transportation: Manual wheelchair, drives his own car.
Interests: Returned to pre-injury employment for two years after injury then he made the decision to retire.
 Invested small settlement and set up accessible workshop behind his house.

The latter was a pre-injury interest which he had not had time to pursue.

Dominant interests include long distance wheelchair racing and designing racing wheelchair drive mechanisms.

Goal to race across the United States.

LARRY

Date of interview: October 10, 1990
Year of injury: 1987
Cause of injury: Motor vehicle accident
Level of injury: T8 paraplegia
Age
(at time of interview): 28 years
Living situation: Independent, living alone in apartment
Mobility/
Transportation: Manual wheelchair, drives his own car
Interests: Continues in pre-injury relationship.
 Has completed Grade 11 and 12 and a computer accounting course since injury.
 Currently employed as apprentice setting up new accounting system for a medical supply company.

MALCOLM

Date of interview: August 15, 1990
Year of injury: 1986
Cause of injury: Motor vehicle accident
Level of injury: C6 quadriplegia
Age
(at time of interview): 31 years
Living situation: Lives alone in apartment in a house.
 Requires attendant care in mornings.
Mobility/
Transportation: Manual wheelchair, drives his own van.
Interests: Pre-injury was a singer and musician (mostly piano) sessional and doing venues with his own group. Since the injury he

has produced a commercial tape of self-written and performed music.
He has a long standing drug abuse problem which he has recently begun to acknowledge.

PETER

Date of interview: August 15, 1990
Year of injury: 1986
Cause of injury: Motor vehicle accident
Level of injury: T8 paraplegia
Age
(at time of interview): 39 years
Living situation: Independent. Just before accident he was in the process of building their own home and workshop and living in a trailer on the property. Post-injury he returned to live in the trailer and with the help of friends completed the house.
 Lives with his wife and two children, the youngest child being conceived and born post-injury.

Mobility/
Transportation: Manual wheelchair. Drives his own car
Interests: Continuing work on the house. Recently resumed his former trade as a cabinet maker using his adapted workshop on his property.
 Competitive wheelchair tennis player.

RANDY

Date of interview: June 4, 1990
Year of injury: 1985
Cause of injury: Motor vehicle accident
Level of injury: C4 quadriplegia
Age
(at time of interview): 35 years
Living situation: Pre-injury Randy owned his own home and jointly owned an electrician business with his brother. He had been living with

his partner for several years and they planned to marry that year.

Post-injury he has sold his share in the business to his brother. His fiancée broke off the engagement and they continue to be involved in a court case over his assets.

He is currently living in a group home with three other persons with disability requiring full-time attendant care. He finds this preferable to living with his parents or other members of his family all of whom are supportive and involved in his life.

**Mobility/
Transportation:**

Electric wheelchair operated using forearm support and joystick control. Owns a van which is driven by attendants, friends and family.

Interests:

Through a privately operated foundation he has learnt a number of computer skills and been supplied with equipment. He is currently working for the organization 4 days a week.

He is currently single but notes that as his confidence in public, severely shaken by the injury, is increasing so is his social life improving and diversifying.

BRIAN

Date of interview: August 22, 1990

Year of injury: 1985

Cause of injury: Diving accident

Level of injury: C7 quadriplegia

Age

(at time of interview): 32 years

Living situation: Independent. Living in same situation with partner as pre-injury. They plan to marry in 1991.

**Mobility/
Transportation:**

Manual wheelchair. Drives his own car.

Interests: His partner's sister married a person with quadriplegia just prior to Brian's accident. This man has the same injury level as Brian but was injured 15 years ago.
Completed high school and is now working as a counsellor.
Plays competitive wheelchair rugby.
They have just bought their own home.

DIRK

Date of interview: August 29, 1990
Year of injury: 1985
Cause of injury: Motor vehicle accident
Level of injury: C5 quadriplegia
Age (at time of interview): 35 years
Living situation: Pre-injury he owned his own house, living with his wife and two sons. Post-injury he returned to this same setting. Two years post-injury he and his wife divorced and she kept the house. He moved into a group home with three people requiring full-time attendant care.
 A year later he remarried and moved into an apartment with attendant care. He is currently awaiting a divorce from this second marriage and is living alone with his dog with attendant care in mornings and evenings.
 He is in a committed relationship but intends to maintain separate living arrangements for the present.

Mobility/Transportation: Electric toggle controlled wheelchair.
Drives his own van.

Interests: He spends valued time with his sons and has a good friendship with his first wife.
He has completed secondary school and is planning more education. He has been

working as a consultant with B.C. Transit.
His latest goal is to return to his pre-injury interest of sky diving.

DOUGLAS

Date of interview: August 14, 1990
Year of injury: 1985
Cause of injury: Motor vehicle accident
Level of injury: C5 quadriplegia

Age
(at time of interview): 26 years
Living situation: Post-injury Douglas lived in a cooperative apartment with his brother. For past two years he has lived alone with his dog with attendant care in the mornings and evenings. He is single and not currently in a committed relationship.

Mobility/
Transportation: Electric toggle controlled wheelchair
 Uses public transportation

Interests: Post-injury he worked as a computer teacher at a rehabilitation centre part-time.
 Currently he is a full-time student at a community college. He majors in a B.A. in History May 1991 and plans to commence an education degree program at university in September 1991. His goal is to become a history teacher.

IAN

Date of interview: October 2, 1990
Year of injury: 1985
Cause of injury: Motorcycle accident
Level of injury: T8 paraplegia

Age
(at time of interview): 32 years
Living situation: Married three years before injury, no children, employed as a printer. Post-

injury returned to their pre-injury home renovated for his needs and to his previous employment.

During first three years post-injury Ian supported his wife through nursing program.

Mobility/

Transportation:

Manual wheelchair. Drives his own car and pick-up truck.

Interests:

Ian uses a motor bike designed and built by him and friends.

At the time of his injury Ian and his wife were told that he was infertile.

With evolving knowledge this prognosis was proved wrong. They have a daughter born in 1990. His role as parent is of central importance to Ian.

APPENDIX B

Sample Interview Questions

Open ended non-structured questions were chosen as the format of each interview. It was hoped that this format would facilitate the expression of each individual's experience of spinal cord injury over the years post-injury. The following are examples of some of the questions asked:

What would you describe as being 'successfully' rehabilitated? Would this describe you?

Imagine the years since your injury as a journey. Could you describe what was most significant to you (influenced you the most) during that journey?

How have you made some meaning out of that journey?

Is there a particular feeling you experience when you think of the experience of learning to live with a disability?

Have your feelings about the experience of the past few years changed over time?

Has there ever been a time when your way of thinking about the experience of spinal cord injury has seemed different than those around you?

Is there anyone you know who thinks about spinal cord injury and its consequences differently than you for example, other injured persons, health professionals, friends, strangers)?

How do they think about it?

How is that different from the way you think about it?

What would you describe about your experience to someone newly injured or someone who knows nothing about spinal cord injury?

How does this experience and the person you are now relate to the person you were before the injury?

How did you pre-injury personality contribute or hinder your learning to live with the disability resulting from spinal cord injury?

Before your injury did you have any involvement or contact with a person with a disability? If so can you describe your reactions to them?

After all we have talked about (in the end) what does your experience mean to you?