

PHYSICAL ACTIVITY AND SPORT AFTER SPINAL CORD INJURY:

AN INSIDE PERSPECTIVE

by

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B.Sc. P.T., The University of Alberta, 1994

A THESIS SUBMITTED IN PARTIAL FULFILMENT OF

THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF SCIENCE

in

THE FACULTY OF GRADUATE STUDIES

(School of Rehabilitation Sciences)

We accept this thesis as conforming
to the required standard

~~THE~~ UNIVERSITY OF BRITISH COLUMBIA

April 2001

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ABSTRACT

The spinal cord injured (SCI) population has been shown to be at risk of developing serious secondary complications after injury and many authors have attributed this in part to a sedentary life style. Consequently, this study was designed to examine the issues that encourage and discourage participation in physical activity and sport after a SCI. In recognition of the profound influence of society on disability, it was deemed important to explore fully the social, as well as individual, issues that affect participation.

Semi-structured interviews were used to explore the experiences of individuals with paraplegia concerning their experiences with physical activity and sport. Analysis of their statements led to the development of overarching themes that were compared to the growing literature on disability and sport and physical activity.

Through the words of eight participants, this study has confirmed the potential importance of physical activity and sport in an individual's life post-injury. More importantly, participants credited activities with providing profound meaning to their lives and a method of contrasting societal stigma as well as creating a positive identity. The potential role of physical activity in assisting in this process emerged as a predominant theme.

The participants' narratives provide evidence that social factors do play a large role in enabling or disabling their participation in sport and physical activity after SCI. In addition to citing environmental barriers such as accessibility,

availability of resources and equipment, and attitudinal barriers of others; their stories also reveal an internal process of redefining self that occurs after injury which profoundly impacts participation.

This internal process, however, is likely in turn influenced somewhat by societal ideals, again outlining the profound influence of society. Consequently, the answer to the question 'What factors determine whether an individual will participate or not participate in physical activity and sport following a SCI?' appears to be complex, involving both internal and external factors. The information gained through the narratives of these eight individuals can help rehabilitation professionals, planners of physical activity and sport, and individuals with SCI, their families and their friends by providing needed insight into both the personal and societal challenges they face.

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ACKNOWLEDGEMENTS

I would primarily like to thank Dr. Darlene Redenbach (Rehabilitation Sciences) for serving as my Senior Supervisor; for taking the plunge into qualitative research with me and providing constant support, guidance and encouragement. From your numerous hours spent with me in conversation, to your diligent work in reviewing manuscripts, I am grateful for your willingness to work with me over the past three years.

I wish to also express my sincere appreciation to the members of my committee: Dr. Isabel Dyck (Rehabilitation Science) who provided expertise and advice crucial to the formulation of this thesis and insights critical to the organization of the data; Dr. Lyn Jongbloed (Rehabilitation Science) who provided me with supportive suggestions and encouragement throughout; and Dr. Sally Thorne (Nursing) who kindly agreed to join my committee on short notice. Each member of my committee has worked extremely hard with me to achieve our set goals and timeline, and for that hard work I am deeply grateful.

I am also very grateful for the financial support I have received from the University of British Columbia in the form of the University Graduate Fellowship.

I am indebted to the eight participants in this study for sharing their time with me. Your openness and sincerity was greatly appreciated. I am thankful that I have had the opportunity to learn from your stories, and I am certain that your narratives will be helpful to others.

I am certain that my time working on this thesis has been made easier by the strong support I have received from my family and friends, a support network stretching from the interior of British Columbia to the bayous of Louisiana. I particularly would like to thank my parents, Patrick and Sharon, for their never-

ending support and encouragement. Thank you for everything. I also would like to thank my wife's family in Baton Rouge, Louisiana for their constant words of support.

Thanks also to Kona, who sat at my side for every one of the long hours I spent typing and provided me with companionship and stress relief.

Lastly, but by no means least, I would like to express my utmost appreciation and thanks to my wife, Sherri. From your willingness to rearrange your life to support this endeavor to the constant daily support you provide me, I thank you from the bottom of my heart.

DEDICATION

To:

Sherri;

and to the eight individuals who shared their lives with me.

CHAPTER ONE

INTRODUCTION

CHAPTER ONE: INTRODUCTION

Background

The origins of this thesis can be traced back many years, to the summer of 1991. I was completing my first year of undergraduate training for physical therapy and at the time had no inkling of where my career in physical therapy would take me, the places I would work or the people I would meet. I certainly had no notion that I would ever continue with my studies in the rehabilitation field once finished with undergraduate training. Strangely enough, it was events unfolding that summer over three thousand miles away that would eventually have a profound influence on my life and spark the creation of this thesis.

It was July 1991 in a small city in the southeastern United States, and a young woman was, like myself, spending the summer home from university. Just as I am certain I did much of that summer, she was spending a great deal of time with her friends catching up on the latest gossip from friends scattered across university campuses around the nation. This particular young woman had chosen to attend a small college in a nearby state, accepting a lucrative volleyball scholarship. Volleyball occupied a large portion of her time as she had played a great deal of it for the majority of her school aged years, developing her skills to a high degree. Simply put, she loved the game of volleyball. She even loved, although unlikely to admit it at the time, going to practice and performing the same high intensity drills over and over in order to further hone her volleyball skills. She particularly liked the feeling she got when performing her trademark

move, faking a powerful spike and then throwing off the defenders by lightly tipping the ball over their out stretched hands and dropping it into place for a point.

She had always been physically active, playing a range of sports in school. Many of her activities were with the very friends with whom she was now reunited for the summer. She and her friends were invited to a party at an apartment in town and she, like any university student, jumped at the chance to hang out with her friends. However, unknown to her, an argument between drunken young men in the parking lot outside boiled over into senseless violence. Two young men used rifles to retaliate against their adversary. The volleyball playing student was caught in the crossfire as a bullet missed its intended target, passed into the apartment in which the party was occurring, through the chair in which she was sitting and subsequently through her spinal cord.

After a harrowing time in ICU, she would begin rehabilitation, another story with which physical therapists are very familiar. She completed her rehabilitation and returned to the community, armed with a set of skills taught to her by her therapists, intended to enable her to achieve all the activities of daily living (ADL's). Over the years that followed, she returned to all aspects of her previous life; reuniting with friends, returning to school, working, and driving; all the 'regular' life activities. A successful rehabilitation. Right? There was, however, one aspect of her life to which she had not returned: physical activity. Prior to her injury, physical activity made up a significant portion of her life; in fact, it contributed in a significant measure to her self-identity as an athlete and a

volleyball player. There was a large aspect of her 'previous' life that remained unvisited since the injury. It would remain so for a number of years.

This thesis begins with this story for a number of reasons. Primarily, it begins to establish the problem faced by individuals with spinal cord injury (SCI) that this thesis attempts to address. As well, it begins to establish the background from which this thesis arose. The woman in the above story is my wife. However, I did not meet her until years after her injury and subsequent rehabilitation. It was not until well after I had personally observed similar issues in rehabilitation. After completing my undergraduate degree in physical therapy, I worked for a number of years in both outpatient and inpatient rehabilitation centers. During this time, I had begun to notice that a number of individuals had experienced difficulty reincorporating physical activity into their lives after sustaining a life altering injury, such as a SCI. Meeting my wife reaffirmed my observations and grew my interest in examining the issues of physical activity after SCI, culminating in this thesis.

Introduction to the Problem

Individuals with SCI frequently suffer from a number of secondary complications that can seriously impact their general health. These include cardiovascular and respiratory impairments as well as skin breakdown, spasticity, decreased mobility, and a number of psychosocial concerns.¹ Many spinal cord injured persons have been noted to lead relatively sedentary lifestyles when compared to the general population. McColl and Skinner ² stated that fifty-six

percent of individuals with SCI reported participating in less than one half hour of exercise per week. Population based surveys have consistently demonstrated that persons with disabilities are less likely to be physically active than individuals without such limitations.³ Ordinary daily activities are not adequate to maintain cardiovascular fitness in those with SCI⁴ and the resulting sedentary lifestyle can have a serious impact in a population whose physical health is already compromised. The potential exists for many individuals with SCI to descend into a vicious cycle of complications leading to further inactivity, leading to further complications. The increased incidence of complications potentially leads to increased visits to health care professionals and an increase in health care costs for that individual. Aside from the strictly medical complications, a sedentary lifestyle can be a serious obstacle to autonomy and significantly decrease quality of life.⁵

There have been a number of studies reporting beneficial effects from exercise, sport, and an overall increased level of fitness in individuals with SCI. Stotts⁶ reported that among paraplegics, non-athletes had a greater occurrence of medical complications and an increased number of hospitalizations than athletes. Others have demonstrated that with endurance training, spinal cord injured persons are capable of eliciting improvements in exercise performance similar to those seen in able-bodied individuals.⁷ It has certainly been proven that gains can be made in cardiovascular and respiratory function with exercise.⁸⁻¹⁰

However, despite a growing body of literature acknowledging that physical activity and sport have the potential for creating significant improvement in the health of individuals with SCI, few individuals are active. The discrepancy in activity levels found when comparing the general population with those with SCI would suggest that there are common factors that lead to increased difficulties for those with SCI in incorporating such activity into their lives. One study has suggested that among the reasons for the inactive lifestyle frequently found in persons with disabilities are: a lack of knowledge, limited access to transportation, inaccessible facilities and equipment, and a perception by individuals that they are not able to exercise as a result of their disability.¹¹ These findings illuminate the role of society and its structures and policies in limiting individuals after SCI.

Despite many decades of being seen through the impairment-focused medical model, disability in general is now being seen in a different light. A newer model with which to view disability has emerged. In the social model of disability the focus is taken off the individual impairments and 'norms', and shifted to society. Instead of focusing on impairments, the social model looks at how society disables an individual through social, environmental, and attitudinal barriers.¹² Advocates of the social model point out that the medical model places all of the focus on the individual with a disability and fails to address the impact that the environment and society have on creating disability for an individual. Using the lens of the social model through which to view the world, the barriers to individuals with disabilities becoming physically active are no longer created

solely by their impairments but also by the attitudes and structure of the society in which they live. The social model of disability emphasizes that the attitudes and opinions of a society have a tremendous impact on individuals with disabilities. When viewed through the social model, the responsibility for an individual's inactivity must also be shared by society as a whole.

Along with the emergence of the social model of disability, there has more recently been a paradigm shift in health care that somewhat mirrors the shift in disability models, from the medical to the social. Gradually, there has been a change in emphasis from health care being the primary prevention of disability to becoming more of a focus on the prevention or reduction of secondary health conditions in people with disabilities.¹³ In rehabilitation, we have observed the beginnings of this paradigm shift, mirrored by an increase in terms such as 'client centered care'. Yet how well are we adapting our ways? Much of the focus of current rehabilitation programs remains on a standard template of activities of daily living (ADL) and mobility instruction, and neglects the long-term health needs of the SCI population.¹⁴ Length-of-stay time in almost all rehabilitation facilities is decreasing. This leads to a focus on immediate ADL and mobility concerns, leaving a limited amount of time for education on living with a disability over the long term. Is rehabilitation failing to address the long-term needs of its clientele? Moreover, when is the right time for such far-sighted education to begin?

Regardless of the degree to which the mitigating factors can be ascribed to society, the structure of rehabilitation or upon the impairments and

perspectives of the individual themselves, it can be agreed upon that individuals with SCI are not leading as active lives as the general population. In fact, relatively little is known regarding the initiation of activity after recovery from SCI.

Rationale for this Study

This study was designed to explore the issues of physical activity after SCI in a unique and comprehensive way. In a response to a recognition of the marked influence of society on individuals with SCI, the thesis was informed primarily by the social model of disability. As noted above, the social model of disability illuminates the marked impact of societal structure, policy, and attitudes on those with SCI, and it is central to the research question. However, as noted by Crow¹², an analysis of disability purely through the lens of the social model may be incomplete and misleading. Accordingly, there is also recognition of impairment and other individual influences in order to present a more thorough evaluation of the issues arising. With this dualistic view, this study provides an extensive understanding of the obstacles faced by individuals with SCI in becoming physically active.

By utilizing a qualitative design, seldom seen in physical therapy literature, this thesis is able to examine issues surrounding activity after a SCI in the only way meaningful to those living the experience; in their own words. Through semi-structured interviews, in-depth and personal views were illuminated through the eyes of the individuals actually living with the daily challenges of SCI. Analysis of the transcripts of the conversations, which formulate the data for this thesis,

revealed insights and information unlike any other in the SCI literature to date. There is, in fact, a rather large gap in the literature addressing the issues of the adoption of physical activity after a SCI. The vast majority of the literature to date addresses physical activity in a quantitative, reductionist way, measuring increases in maximal oxygen uptake (VO_{2max}) for example. Little has been published examining the challenges faced by individuals with SCI in a meaningful, personal way. This gap is particularly notable in the physical therapy literature, with the few qualitative studies in this area being undertaken in other fields, such as recreation therapy.

The rehabilitation field seems to be partially failing in achieving its goals of assisting its clientele to live active, productive lives. A study such as the one undertaken in this thesis will begin to unravel the complexities of the obstacles faced by our clients in returning to active lives, and will provide a stepping stone for further exploration in the area.

Outline of Thesis

Chapter Two consists of the review of the relevant literature, outlining the possible physical consequences of SCI, and the potentially helpful role of physical activity in addressing these concerns. Barriers to an individual's participation in physical activity, as outlined in research to date, are discussed. The chapter also includes definitions of impairment and disability, as well as physical activity and sport, as they were utilized in this study. Literature pertaining to the two contrasting viewpoints of disability, the medical model and

the social model, are discussed and their relevance to an individuals participation in physical activity and sport commented on, establishing the framework for the theoretical approach of this study. At the conclusion of the chapter, the research question is stated.

Chapter Three explores the choice of a qualitative methodology, and examines my positionality with respect to both disability and physical activity and sports. The methods and logistics of the research are outlined, the participant selection and demographics of the participants are described, and the questions that formulated the interviews are discussed. A description of the data collection process and the simultaneous analysis of the data are included. Chapter Three concludes with a description of the themes emerging from the data.

Chapters Four and Five consist of the results of the study, the themes arising from the words of the participants. The results are split into the two chapters, separating the internal, personal struggles from the issues faced in the larger societal arena. In Chapter Four, the loss of identity occurring after a SCI, the process of redefining self, and the role that physical activity and sport can play in that process are illustrated in the participants own words. Issues of gender are also discussed. In Chapter Five, participant insights are used to discuss societal barriers to participation in physical activity and sport. From physical access to the availability of resources and the attitudes of those around them, the factors both encouraging and discouraging are discussed. After a consideration of the role of physical activity and sport in changing perspectives of

disability, the impact of the individuals' personal perspectives of their disability is addressed.

In Chapter Six there is a broader discussion of the results, expanding to issues of relevance in the broader social environment. There is a reflection upon the major issues revealed by the men and women of this study, and upon the role the social model can play in enhancing understanding of the issues faced by those with SCI attempting to participate in physical activity and sport. The relevance of the findings of this study to rehabilitation, planning of physical activity and sport, family and friends of individuals with SCI, as well as individuals with SCI and society as a whole are discussed. Finally, the implications of this research to future research are considered.

CHAPTER TWO

LITERATURE REVIEW

CHAPTER TWO: LITERATURE REVIEW

Physical Consequences of Spinal Cord Injury

A SCI in itself is a devastating injury, yet the impact on the individual is not limited to the subsequent paralysis. Almost all systems of the body are affected. With time, not only the damaged spinal cord and related musculature are of concern, but also the vast number of secondary complications that can develop throughout the body. Knowledge of the medical complications that often arise after SCI is essential in order to fully appreciate the potential benefits of physical activity in this population.

A number of epidemiological studies have examined the incidence and prevalence of illness in the SCI population and determined the primary causes of morbidity and mortality.¹⁵⁻¹⁸ Although the numbers reported vary depending on the location and extent of the study, common trends emerge. The major systems involved with morbidity and mortality in all reports were the cardiovascular, respiratory, and urinary tract systems.¹⁵⁻¹⁸

With a SCI above the sixth thoracic vertebra there is a diminished sympathetic innervation of the heart¹⁹, seriously impacting the normal cardiovascular response to exercise. There is a lower maximum heart rate in tetraplegic persons and individuals with high level paraplegia.¹⁹ As well, the loss of sympathetic outflow causes impaired vasoconstriction, venoconstriction and myocardial contractility.²⁰ These changes cause a decrease in venous return,

reduced stroke volume, and a lower cardiac output¹, leading to a significant decrease in tolerance of activity.

A large percentage of SCI persons also suffer from frequent respiratory problems such as pneumonia, atelectasis and respiratory infections due to a decrease in the active respiratory musculature.²¹ The extent of these adverse effects depends largely on the level of injury. Higher level injuries involve a greater extent of the abdominal and intercostal musculature and consequentially lead to a decreased aerobic capacity and diminished ability to cough. Complications such as scoliosis and spasticity of the abdominal musculature can also negatively affect respiratory function.

Urinary tract infections have also been noted to be prevalent in persons with SCI.^{22, 23} The health risks associated with this may carry special consequences. It has been recently suggested that there may be a link between recurrent urinary infections and an increased risk of cardiovascular disease in persons with SCI. In a recent letter to the journal *Spinal Cord*, SCI researchers hypothesized that this link may exist through increased levels of a substance called C-reactive protein, a marker of the acute phase response to infectious agents, immunologic stimuli, and tissue damage.²³

A number of other complications may also occur after SCI, particularly associated with a significant decrease in activity levels. Chief among these problems are pressure sores^{24, 25}, and bone loss.^{26, 27}

Physical Activity and Spinal Cord Injury

Prior to any further discussion of physical activity and sport, it is appropriate to define the way in which these terms are conceptualized in this study. Certainly, physical activity levels can vary greatly from individual to individual and a universal definition does not exist. As the goal of this thesis is to explore the experiences of a number of individuals with SCI, no definite limitations on the term physical activity were outlined and a broad conceptualization has been accepted. In this thesis, physical activity and sport are thought of as including a broad range of activity, from informal and unstructured physical activity for fitness and fun to competitive sport. Team and individual activities, as well as more recreational activities with family and friends are considered. In this way, there is an acknowledgement of the potential benefits of any physical activity.

Acknowledgement of the benefits of regular physical activity has certainly existed for thousands of years. Hippocrates (460-377BC) stated that "all parts of the body which have a function, if used in moderation and exercised in labors in which each is accustomed become thereby healthy, well developed, and age more slowly, but if unused and left idle, they become liable to disease, defective in growth and age quickly." ^{28 pg. xv} A number of more recent investigations have echoed this ancient advice. Two recent studies published in the New England Journal of Medicine ^{29, 30} have reported that physical fitness appears to be a graded, independent long-term predictor of mortality. Furthermore, beginning moderately vigorous sports activity was associated with lower rates of death from

all causes. The benefits of initiating physical activity appear to apply to all individuals, and gains have also been demonstrated in those over sixty-five³¹ and those with disabilities.³²

The first person credited with recognizing the significant beneficial effects of exercise and sport in the SCI population is Sir Ludwig Guttmann, MD.³³, founder of the National Spinal Injuries Center in England. Recognizing the physical and mental value that they could provide, he introduced sporting activities as an integral part of the care of a spinal cord injured person. Sir Ludwig was instrumental in the creation of the Stoke Mandeville Games for the Paralyzed in 1948, an event which grew annually to become what we now know as the Paralympic Games.³⁴ The recent Paralympics, in Atlanta, Georgia in 1996 involved nearly 3,500 athletes from 120 countries throughout the globe.³⁴ As one of the many spectators at this event, I was struck by the incredible athletic feats achievable by the "disabled" athletes. Many had achieved substantially high levels of physical fitness. Certainly, the physical impairment of SCI was not necessarily a limiting factor for participation in physical activity. Yet there is still a large discrepancy in the involvement of spinal cord injured persons in physical fitness activities when compared to the general population.^{2, 3} Factors other than impairment must contribute to the creation of such a disparity of involvement. Uncovering the factors leading to this diminished participation in physical activity is certainly important, as the consequences of a sedentary lifestyle for individuals with SCI can be significant.

A study of individuals with tetraplegia by Dallmeijer and colleagues³⁵ used multiple regression analysis to examine the determinants of physical capacity, quantified as maximal power output, peak oxygen uptake and maximal isometric force. They discovered that other than the unmodifiable factors of level and completeness of lesion, the most important determinant of physical capacity was level of sport activity, defined as hours of sport participation per week. Similarly, Noreau and colleagues³² reported that there was a significant influence of fitness status on functional ability in SCI persons. More specifically, studies have reported that paraplegic individuals who are involved in competitive wheelchair sports are more successful in avoiding major medical complications than those not involved, saving themselves and the state the expense of medical care and hospitalizations.⁶ These results compared favorably with those of Curtis and colleagues³⁶, who reported that spinal cord injured athletes demonstrated a trend towards fewer medical complications and re-hospitalizations. Krause and Kjorsvig¹⁵ reported one of the significant differences between SCI persons surviving after a four year period and those passing away was the level of activity.

Though varying slightly from study to study, the leading causes of death for both paraplegics and tetraplegics are heart disease and respiratory disease.³⁷

³⁸ A number of studies have reported significant improvements in cholesterol profiles of active SCI persons, with a concomitant decrease in risk of heart attack.^{35, 39, 40} It was noted that there was a significant association between sport activity in the year post injury and more favorable risk profiles at two years post

injury³⁵, and that although not achieving a profile on par with able bodied controls SCI athletes demonstrated a much better lipid profile than inactive individuals with SCI.^{39, 40} As well, a number of studies with SCI individuals have shown that meaningful improvements in cardiopulmonary fitness can occur with several weeks of endurance-type arm exercise.⁴¹⁻⁴³ Evidence also exists that exercise training positively affects respiratory function in tetraplegic persons.¹⁰

More trivial, although potentially serious problems such as pressure sores also diminish with increasing involvement in sport and activity. Sumiya and colleagues²⁵ and Stotts⁶ both found that those with SCI who were more active had a decreased incidence of developing pressure sores. In the study by Sumiya and colleagues, cited above, the incidence in the non-active group was more than double that in the active group. Saltzstein and colleagues⁴⁴ discovered that another potentially serious complication of SCI was attenuated by increased activity levels. They reported that there was a definite correlation between increased mobility and bone density, therefore leading to a decreased risk of fractures.

The physical effects of a SCI can be potentially devastating, yet often are only a part of the overall impact of such an injury. Studies have noted that depression can follow such an injury.^{45, 46} Studies in the general population have shown that mood can be improved by an increase in the activity level and participation in pleasant events⁴⁷, and there is no reason to believe that this would be any different in the SCI population. As well, recent studies in both the SCI population and the general population have investigated the effects of

exercise on raising levels of serotonin, with positive results of possibly creating mood elevating effects.⁴⁸

As well, a number of studies have found that sport competitors, whether disabled or not, demonstrate an improved psychological profile with lower levels of tension, depression, and fatigue and higher levels of vigor, self esteem, and perceptions of health.^{49, 50} Regardless of the level of sport or recreation, these findings held true.⁵⁰ The positive changes in mood appeared to result simply from participation in sport and were not contingent upon competitive level.⁵⁰

Self-perception, easily affected by disability, can also be impacted significantly by participation in sport and physical activity. Hedrik⁵¹ found that participation in wheelchair tennis significantly improved the individual's general perceptions of their physical competence. These findings were supported by Greenwood and colleagues⁴⁹ in another study examining self-efficacy and psychological well being in wheelchair tennis participants. They defined self-efficacy as an individual's perceived confidence about completing a course of action necessary to attain a designated outcome.^{49pg. 13} This could also be thought of as a situation-specific self-confidence. Greenwood and colleagues reported that "participation in competitive sport may raise the individual's perceptions of their physical capabilities through performance accomplishments on sport skills." The most important finding, however, has been that the increase in self-efficacy can extend beyond the sport itself into other areas of the individual's life. In the study by Greenwood and colleagues⁴⁹ self-efficacy for wheelchair tennis was positively related to self-efficacy for wheelchair mobility

tasks. Individuals participating in wheelchair tennis developed increased confidence in the physical abilities needed for their everyday mobility. There appears to be a 'transference' of ability that occurs for individuals whereby success at one activity can increase ones feeling of confidence in performing other tasks. It would seem then that participation in sport can have a definite impact on changing the self-perceptions and attitudes of individuals with disabilities.

Despite all of the mounting evidence supporting the health benefits of exercise and sport in the SCI population, the principles pointed out thousands of years ago by Hippocrates and embraced over fifty years ago by Sir Ludwig Guttmann have yet to take hold in the rehabilitation community. Sadly, despite the strong scientific evidence and calls for a stronger emphasis on exercise and conditioning programs^{32, 52}, it is my experience that physical activity and sport post-discharge are still not addressed sufficiently by rehabilitation professionals in the care of SCI persons. With earlier discharges becoming the norm, individuals are perhaps not able to, or not ready to, address physical activity and sport issues while in rehabilitation. If this is so then the system fails to address the needs of individuals after their discharge when the issues of physical activity and leading a healthy lifestyle are particularly relevant. Many individuals with SCI do not appear to be incorporating physical activity and sport into their daily lives and many seem to fall into a vicious cycle of inactivity and medical complications.

Barriers to Physical Activity

Certainly, when compared to the general public spinal cord injured persons have been shown to lead relatively sedentary lifestyles. McColl and Skinner ² reported that individuals with SCI were less likely to become involved with physical activity and sport, with over half of their sample population of individuals with SCI reporting minimal amounts of physical exercise. Moreover, population based surveys have consistently demonstrated that persons with disabilities are less likely to be physically active than individuals without such limitations.³ It would stand to reason that if the issues surrounding the incorporation of physical activity into ones life were similar after a spinal cord injury to those found in the general population the rates of involvement would be similar. Although the research is limited, it was noted earlier that there is a notable discrepancy in participation. Therefore, it would follow then that there must be differences in the 'barriers' experienced by the two groups.

There is a paucity of information on physical activity for persons with disabilities and despite the voluminous amount of research done in the general field of exercise science, little is known regarding the barriers to physical activity perceived by those with disabilities.⁵³ In the general population, many studies have found time constraints^{54, 55}, and a lack of motivation^{56, 57} or "laziness"⁵⁸ to be the prime reasons for failing to incorporate physical exercise into ones lifestyle. Rimmer and colleagues, in a recent study of women with disabilities found that the primary barriers to exercise reported by the subjects were quite different.⁵³ In this study, cost, transportation, and a lack of knowledge of a community or sports

facility were identified from a list of barriers described as the chief inhibiting factors. Certainly accessibility of facilities, and of the environment in general, would be expected to be an issue for those with a SCI and have been reported as a chief factor in previous studies. In a study discussing returning to the community with a SCI, Datillo and colleagues⁵⁹ cited a number of instances in which participation in recreational activities was blocked due to a lack of either access or transportation. The following quotes from participants interviewed elucidate these issues:

Lack of accessibility of the place ... we may be going sometimes gets in the way and prevents me from going out and doing certain activities.^{pg.21}

I don't have a car. I don't have a van yet so there's no way I can get out by myself.... I just don't have the transportation.^{pg20}

The recent study by Rimmer and colleagues referred to above noted the significant lack of information regarding physical activity in individuals with disabilities and stressed the critical need to study barriers to physical activity in persons with disabilities. However there is an issue of critical importance that cannot be overlooked when examining this study, and the vast majority of others examining barriers experienced by individuals with disabilities. Rimmer and colleagues reviewed the literature themselves and developed a telephone survey to be administered as the method of collecting data. It was the researchers that decided upon the list of barriers and the individuals with disabilities were able to only respond with a 'yes' or 'no' to the majority of questions. In the present study,

a qualitative method of semi-structured interviewing was chosen to provide participants with the latitude to respond to the issues surrounding participation in physical activity in ways that are personally meaningful and relevant. In this way, this study is able to expand upon the existing literature in a unique and comprehensive way, allowing the voices of those with SCI to come through.

Definitions of Impairment and Disability

Before progressing to a theoretical dialogue on disability, it is important that definitions and use of words such as 'disability' or 'impairment' are clear. Probably the most widely known and debated definitions arose from the World Health Organization's (WHO) International Classification of Impairments, Disabilities, and Handicaps (ICIDH) in the early 1980's.⁶⁰ That document outlined the following definitions:

Impairment: Any loss or abnormality of psychological, physiological, or anatomical structure or function

Disability: Any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being

Handicap: A disadvantage resulting from an impairment or disability, that limits or prevents fulfillment of a role that is normal, depending on age, sex, social or cultural factors for that individual.⁶⁰

The medical model, discussed below, assumes a cause and effect relationship between impairment, disability and handicap. An individual's

limitations (impairments) are the principal cause of their disadvantages and the approach is to treat or cure the impairments.

Newer perspectives on disability such as the social model, which will be discussed below, lead to the creation of different definitions of impairment and disability as well as a significant change of viewpoint. The social model of disability shifted the focus from impairment to disability, with disability reflecting more of disabling social, environmental, and attitudinal barriers rather than a lack of ability.¹² Viewed solely through this light, impairment remains a functional limitation affecting an individual's body, however disability is now viewed as "the loss or limitation of opportunities resulting from direct or indirect discrimination."^{12pg.208} Management of disability therefore is viewed as multifaceted, requiring social change, as well as environmental modifications.

In recognition of the changing views of disability the WHO has revised the ICDH and created the ICDH-2, which was fully released in 2001.⁶¹ The new version is based on an integration of the two opposing views mentioned above. The new ICDH-2 is intended to be applicable to all human beings, with a recognition of the environment, and society as influences on an individual. Impairment remains defined as a "problem in body function or structure as a significant deviation or loss."^{61 pg.16} Disability is an umbrella term for problems with body structure or systems, performing activities, or participating in any area of life.

Throughout this proposal the “modern” definitions of impairment and disability, those brought forth by the social model and outlined in the ICIDH-2, will be utilized. All references to disability and impairment can be viewed in this way.

Theoretical Considerations

Medical Model

The benefits of physical activity and sport for individuals with SCI can be viewed through a traditional medical model perspective. With this viewpoint, exercise is a modality that can serve to maintain or lessen impairment and therefore decrease disability. For example, strengthening the upper-body muscles of an individual in a wheelchair leads to an increased ability to wheel up a steep ramp, therefore decreasing their disability and perhaps enabling him/her to enter places previously unattainable. A general increase in health and physical ability will most likely lead to a decrease in disability, however, viewing the issues in this fashion fails to address the more relevant issue of what helps or hinders involvement in physical activity. There is little argument that an individual can experience both physical and psychological benefits from participation, yet studies have also shown a lack of parity in the involvement of able bodied individuals and those with SCI. This is a critical issue that the medical model cannot address, because this one-sidedness is likely not due to physical impairments alone. People with disabilities are similar to the general public in their ability to increase fitness levels through exercise and therefore increase their abilities. People with disabilities may actually gain more from exercise and

physical activity than the general public because they often start at a lower level of conditioning. Yet, because people with disabilities are less likely to participate in physical activities than the general public^{13, 59}, there must be other factors preventing these individuals from participating. As alluded to earlier, the literature to date suggests accessibility, transportation, and cost are factors. Perhaps, as with the general public, a lack of motivation or time constraints also limit participation. Regardless of the specific factors, it is apparent that the medical model is unable to reveal a complete view of the barriers to participation. The issues surrounding involvement and initiation of activity are perhaps better viewed through the social model of disability.

Social Model

The social model of disability developed in the 1970's and 1980's when authors such as Hahn, Abberley, and Oliver⁶²⁻⁶⁶ highlighted social and political influences on disability. Such authors noted that disability could be viewed as a form of oppression and discrimination. This view of disability shifts the focus from individual impairments and 'norms' to a focus on society. Instead of emphasizing impairments, the social model examines how society disables an individual through social, environmental, and attitudinal barriers.¹² Using the lens of the social model to view the world, the barriers to individuals with disabilities becoming physically active are no longer created solely by their impairments but also by the attitudes and structure of the society in which they live.

Western society has long viewed disability in a very individualistic way, with little regard to how society may serve to create and impact disability. Well into the mid-twentieth century, disability was viewed as a personal tragedy ⁶⁷, with no recognition of society's role in creating or being responsible for those with disabilities. Abberly notes that impairment and disability cannot be thought of as an unavoidable fact of nature, but as something in which society plays a large causal role.⁶² He notes that large numbers of people around the world are injured at work daily while producing products for society. In addition, the products created, such as prescription drugs, are implicated in the creation of impairment. Abberley⁶² cites Thalidomide as an infamous example of society's role in the creation of disability. It is also of note that the distribution of disability is not equal around the globe. Of the hundreds of millions of individuals living with disabilities around the world, over two thirds are estimated to be living in developing countries.⁶² It is clear that impairment is not just an unfortunate "act of God", but highly influenced by social and political factors.

In addition to actually creating impairment and disability, it is society that defines what is and is not considered disabled. Oliver ⁶⁶ compares an individual with infantile paralysis and a person with a boil on his/her foot. Both individuals may limp or need crutches, and both will have difficulty with mobility, yet we would likely only define one as being disabled. It is society that delineates what qualifies as a disability and what does not.

Disability can in fact be viewed as a normal, universal aspect of the human condition.

No human has a complete repertoire of abilities, suitable for all permutations of the physical and social environment. Scientifically speaking, there are no inherent or intrinsic boundaries to the range of variation in human abilities; ability-disability is a continuum and the complete absence of disability, like the complete absence of ability, is a limiting case of theoretic interest only.^{68pg.1182}

Looking at disability/ability this way, along a continuum, it depends entirely upon where society draws the boundaries as to whether or not someone is considered "disabled." Furthermore, these arbitrary boundaries are "drawn for social and political purposes, and as such are not facts of the world."^{68 pg.1182}

Society has been very slow to acknowledge its role in creating and perpetuating disability. After World Wars I and II, the presence and recognition of individuals with disabilities began to increase and governmental programs were developed to help provide support.⁶⁷ However, it was not until a few decades later, in the nineteen seventies, that a new social and political view of disability emerged. This was the beginning of what is now referred to as the social model of disability.^{62, 64-66} At this time disabled persons groups began to become active in demanding their human rights ⁶⁷, and individuals with disabilities were coming to be viewed as an oppressed group. Hahn ⁶³ notes that individuals with disabilities are similar to other oppressed groups that have launched major social and political movements in America; notably women and racial and ethnic minorities. He points out that there are three major similarities between racial/ethnic groups and those with disabilities; the experience of discrimination

and segregation, being visibly and notably different, and having a permanent difference not of personal choice.⁶³

As the recognition of mitigating factors such as those noted above continues to take a stronger foothold in society today, physical disability is becoming increasingly acknowledged collectively as a social, economic and political issue and not solely as an individual medical concern. Yet society's tendencies towards a deeply rooted individualistic and medicalized structure are hard to change and individuals with disabilities continue to encounter barriers; not only architectural barriers, but barriers created by prevailing public attitudes and views. It can be particularly difficult for individuals with impairments to develop a sense of self worth and a positive self identity in an industrial society in which productivity, and efficient and structured time use are of prime importance.⁶⁹ This same society also places great importance on appearance and physical ability, with strong ideals of bodily perfection that those with disabilities cannot meet.⁷⁰ Certainly, the social model of disability emphasizes that the attitudes and opinions of a society have a profound impact on individuals with disabilities.

When examining the issues surrounding participation in physical activity after SCI, it is clear that factors outside of the individual's impairment likely play a role. Individuals with SCI face architectural barriers, as well as altered public attitudes and expectations regarding physical activity. When individuals with SCI are viewed as a minority group facing a degree of societal oppression, the path to participation in physical activity is not an easy one. Clearly, in exploring the

issues surrounding participation in physical activity after SCI, an analysis informed by the social model of disability is most appropriate.

However, it would not be prudent to accept the social model as the only theoretical vantagepoint from which these issues can, or should, be viewed. The social model of disability, in its aim to move away from the medical model, has received criticism for placing responsibility solely on society and ignoring the influence of the individual and their impairments¹², in a sense swinging the pendulum from one extreme to the other. A strict adherence to only the principles of a social model of disability has been viewed as being potentially detrimental to individuals with disabilities, serving only to portray them as helpless victims of social oppression.⁷¹ Crow observed that a purely social model view, with no recognition of the individual or their impairments did not paint an accurate picture of disability.¹² She noted that an individual's participation in an event could be limited due to limited energy or pain, regardless of the degree of accessibility or acceptance. Crow ¹² was concerned that an exclusively social view of disability provided only a partial view and risked excluding those with disabilities that faced difficulties regardless of society's provisions. Ironically, the social model, with no recognition of impairments, could contribute to the exclusion of individuals with disabilities that limit their function regardless of society's role. Crow ¹² recognized the profound effect impairments can have and called for a renewed social model; one allowing for a recognition of the role of impairments and of the individual, not only society.

The Social Model Related to Physical Activity and Sport

The social model of disability emphasizes that social attitudes have a tremendous impact on individuals with disabilities. To an individual using a wheelchair, an inaccessible fitness center means more than just an architectural oversight. It is a reflection of society's values and attitudes. It can only mean that society does not consider it important for them to exercise, or perhaps they are not able to or should not exercise. An inaccessible pool or gymnasium tells an individual with a disability that recreation and sport is unnecessary for them, or that they can't participate in sporting activities; that they do not belong. Unfortunately, the message provided by society can become accepted as truth, not only by the general public, but also by the individual with a disability as well. If an individual with a disability is told often enough that they aren't to be involved in sporting activities and that physical activity is only for the able bodied, they will begin to accept the message as truth. This socialization into accepting oneself as inferior or unworthy has been referred to as internalized oppression, which is reinforced by segregation, negative images, cultural representation, absence of positive role models, and social treatment of disabled people.⁷² Individuals with disabilities can become passive recipients of societal belief systems, particularly the societal labeling of a disability as the individual's "master status."⁷³ In an industrialized society focused on productivity, individuals with disabilities often have difficulty using their time meaningfully and feeling as though they have accomplished something.⁶⁹ Society reinforces the feeling of inadequacy derived from a lack of productivity. It is in this society that individuals with disabilities, not

surprisingly, develop a feeling of inadequacy and inability concerning physical activity and sport, as well as in other aspects of life.

One major aspect of society that limits participation in physical activity and sport is the obsession in western society with bodily perfection. Almost everywhere you look today there are slick advertising campaigns promoting products by showing young, healthy, active people with athletic or muscular figures. Western society especially has strong ideals of bodily perfection and the disabled do not fit into this ideal.⁷⁰ Certainly when it comes to athletic endeavors, those with 'disabled' bodies are not expected by society to achieve greatly. In fact, for individuals with disabilities societal expectations of the body's physical capabilities are often exceedingly low.⁷³ The failure to control one's body is one of the most powerful symbolic meanings of disability⁷⁰, and often in an individual in which the body represents obvious disability it is devalued and viewed as a limiting force.⁷³ Assumptions about the physical capabilities of individuals with disabilities are likely based exclusively on appearances, despite having no knowledge to support these assumptions. Due in part to these assumptions and low expectations, the individual with a disability could easily develop a poor self-perception of their own physical competencies, focusing on their disability rather than their abilities.⁷³ If the message sent by society is that the disability is the main focus, then that is what it will become.

One further difficulty for the individual with a disability wanting to become involved in sporting activities is often the social isolation that they experience. It is not so much isolation from family and friends, which can also occur⁶⁹, but an

isolation from their sport and from others involved in the sport. Many sports have their own culture and becoming involved in a sport involves becoming accepted and socialized into that culture.⁷⁴ It is a process of acquiring the social characteristics that distinguish them as a 'wheelchair racer' or a 'basketball player' ⁷⁴, and from this developing a positive identity. Often with limited opportunities to participate in sport, and little guidance from other disabled individuals, an individual with a disability is denied the opportunity to become part of a social group of peers. One quadriplegic, a subject in a recreation study, reported:

"I'd like to be around... some people who have common interests and, you know, who would have an influence on me to motivate me to do different things. I'm not around many people like that right now."⁵⁹ pg.20

If unable to participate in sports with peers, an individual with a disability is more likely to feel out of place and self-conscious, leading to increased anxiety and dissatisfaction with the sport. A study by Hedrik⁵¹ found that physically disabled adolescents participating in wheelchair tennis with other physically disabled adolescents significantly improved their perceptions of their physical competence and improved their tennis skill. However, when playing tennis with able-bodied adolescents, the individuals with disabilities displayed no improvement in tennis skills. The participation of able-bodied participants was found to have "significantly exacerbated the anxiety level experienced by disabled participants."⁵¹ It would appear to be of no surprise that the anxiety levels would raise as the disabled individual is confronted by societal norms and

their inability to perform at the same level as an able-bodied individual is reinforced. When forced to participate in a sporting activity with able-bodied individuals the disability is highlighted as the limiting factor and the structure of the activity is designed in such a way as to place them at a disadvantage.

Is it all negative?

It is readily apparent that the social model is helpful in identifying the problems existing that limit people with disabilities from participating in physical activity and sport. However, one must not then conclude that participation in physical activity and sport must be a negative experience for those with disabilities. There are a number of ways in which physical activity and sport can serve to benefit the individual, and these can also be highlighted by the social model of disability.

As noted above, one aspect of society that was highlighted by the social model of disability as creating barriers to individuals with disabilities were the attitudes prevailing in society. Viewing disability through the social model allowed for a view of how the prevailing attitudes in society, as well as attitudes about themselves, hampered efforts by people with disabilities to participate in physical activity and sport. Yet, a number of studies have shown that attitudes and self perceptions are not rigid and with participation in sport, persons with disabilities can serve to change the attitudes of society, as well as their own. As noted previously, in a study examining self-perception in a group of physically disabled adolescents, Hedrik⁵¹ found that participation in wheelchair tennis significantly

improved the individual's general perceptions of their physical competence. These findings were echoed by Greenwood and colleagues⁴⁹ in another study examining self-efficacy and psychological well being in wheelchair tennis participants. There appears to be a 'transference' of ability that occurs for individuals whereby success at one activity can increase ones feeling of confidence in performing other tasks. This phenomenon has also been documented in the able bodied population. In a study by Brody et al.⁷⁵, it was found that individuals who participated in a high risk rappelling task increased their self efficacy towards other high risk physical tasks (rock climbing, automobile racing, downhill skiing) as well as social situations (speaking in front of a crowd, meeting new people). There would be no reason to expect that persons with disabilities would be any different, and comments by persons with disabilities who have participated in recreational activities support this opinion. In one recent study⁷³, a woman with paraplegia, who had participated in a recreational program, described how her involvement altered her perceptions of her abilities in sport and other recreational activities.

I didn't think that I could really participate in that (horseback riding) so, I am more willing to have an open mind about things that I had previously thought, my balance was, totally insufficient for ... because I did [have] the courage for this.^{pg.335}

She adds,

I think I need to be a little bit more open about what I think I can and can't do. I need to give myself a little bit more leeway ... Maybe I can do a little bit more than I give myself credit for.^{pg.335}

Another man with cerebral palsy who had participated in the same study related dramatically how his participation in a fitness program had impacted his life in general when he commented:

Hey, I can do this...I don't have to wait for someone to come and do something for me. It's doing it because I want to, and when, when you feel as though you can act upon the world around you instead of reacting to it, I mean, that's a good feeling, and that spills out, I mean, past the physical training.^{73pg.338}

It would seem then that participation in sport can have a definite impact on changing the self-perceptions and attitudes of individuals with disabilities. In most instances, the experiences gained from physical activity and sport are likely positive because they run counter to the common societal beliefs that emphasize physical disability rather than physical ability.⁷³ As noted earlier, persons with disabilities can become socialized into a passive life due to society's low expectations of ability. It is likely that participation in physical activity and sport gives an individual with a disability an opportunity to challenge and redefine their notions of disability.

These studies demonstrate that positive changes from participation in physical activity and sport can transfer into other areas of the individual's life, allowing them to confront and perhaps challenge the 'disabled role' into which they have been placed by society. Does this same transfer occur for the general public when they view a disabled athlete? If disabled individuals are to ever significantly reduce the attitudinal barriers in society then they must not only

change their self-perceptions of their abilities, they must change the perceptions of the society that limits them. Perhaps physical activity and sport can have a similar effect on the general public, by emphasizing the abilities of individuals and initiating a rethinking of what disability means.

There has been very little research in this area, however it would appear that physical activity and sport can have an impact. When Rick Hansen wheeled his wheelchair around the world, although a great deal of money was raised, one of his main goals was to change peoples' awareness of disability. In his account of his journey⁷⁶, he reflects on the difficulty of changing society's attitudes.

It's easier to give money. You make the donation, watch the papers and TV, see the fund raising go up, feel good about what you've done. Yet giving money can't create awareness. I've know people who've worked for and donated to worthy causes for years, and their awareness level hasn't changed one bit." pg.174.

Yet despite this difficulty, the Man in Motion Tour did seem to change the attitudes of society. Rick Hansen was met at the conclusion of his tour by 50,000 people, mostly able-bodied. He went on to become one of the most respected and well-known Canadians alive today and represented Canada at an international exposition a few years after the conclusion of his tour.

A recent issue of Triathlete magazine⁷⁷ further elucidates the issues of a positive transfer of ability through sport. In this magazine there was an article describing a young ten year-old, named Rudy, who was born with multiple congenital birth defects. He had to have a double above knee amputation a few years later. After spending a great deal of time learning to swim, he now

participates in triathlons. At such a young age he has become very fast and is regularly competing, and winning against able-bodied children. He has become the focus of a great deal of triathlon media, has had major movie and television studios interested in his life story. He has already appeared on public service messages in the United States. As well, he has already been offered a swimming scholarship from the University of Southern California, met with governors, and received a letter from the President of the United States.⁷⁷ There is no doubt that because of his athletic achievements, he has placed himself into the mainstream of culture and is drawing attention that could help to highlight ability rather than disability. His success in a largely able-bodied sport has certainly challenged the conception of disability held by those that have met and watched him. One triathlete noted,

...people are always good to disabled people, but they tend to treat them like disabled people. But here we have this kid –he’s coming after you! He’s not just doing the same events as able-bodied athletes, he’s doing them just as fast.⁷⁷

In the same article, Rudy’s father stated: “He’s showing society that just because you have a disability doesn’t mean you have to be kept in a closet.” It appears from the overwhelming reaction of society to this young athlete, that his success may have an effect on changing the ideas of disability held. Some authors, however, contend that the potential exists for the success of athletes such as Rudy to have a negative impact on society’s views of the disabled, creating a new class of elite disabled and further distancing those with more

severe impairments.⁷⁸ Yet, it does still appear that in a society so infatuated with sport, fitness, and competition the efforts of disabled athletes have the potential to influence perceptions of society. As with the changes seen in self-perception of an individual with a disability, a focus on ability and what can be achieved may change the attitudes of the general public as well. To date no literature has examined this issue.

Earlier, the difficulties individuals with disabilities face fitting in to a very physical appearance oriented world was noted. It was also noted that individuals with disabilities have related that improved physical conditioning changed their view of themselves in a positive way. Examples of this are seen in the following quotes by participants in a fitness program:⁷³ “everytime I can sit up in my chair now...I know that I don’t have to look like somebody’s used accordian.” “ I feel stronger, I feel healthier....I look fit....I feel confident about my ability to just take care of myself... .” It is obvious from quotes such as these that physical activity and sport have the potential to improve an individual’s outlook on their appearance, which can be important in a society so focused on appearance. Although some would argue that a focus on appearance and the body is of questionable importance, it is of note that individuals with disabilities are no different than the able-bodied in that they are also members and products of a society in which appearances are important. Physical fitness and sport appear to provide an avenue by which individuals with disabilities can increase their satisfaction with their bodies.

A final social issue highlighted earlier that can serve to impede the involvement of a person with a disability from participation in physical activity and sport is that of social isolation. This isolation can occur when there is a lack of facilities and programs available, and as such the solution lies in the implementation of such amenities by society. However, social isolation may also occur even in areas where such programs exist. Individuals with disabilities could remain inactive and at home for many of the other reasons mentioned earlier. They may be unaware of opportunities existing. They may be socialized to believe they shouldn't be doing anything, or perhaps the lack of role models to encourage participation plays a role. This is where athletes with disabilities portrayed in the media could be potentially helpful, by becoming role models to other individuals with disabilities.

Once participating in sports or other recreational activities, individuals with disabilities are likely to meet many others in similar situations in a positive environment. Many report that finding a friend with whom to participate is of great benefit and often is the main factor in enabling continued participation.⁷³ Participants in a kayaking program for individuals with spinal cord injury described kayaking as a way to socialize with other persons with similar disabilities but with the emphasis on sea kayaking and not their injuries.⁶⁹ As well as providing a common ground to meet others with similar disabilities, sports and recreational activities can provide a base upon which to relate to able-bodied individuals as well. When performing an activity such as kayaking, for example, once out on the water there is little difference between an individual with T12

paraplegia and an able-bodied individual. In this case the common threads of outdoor recreation, activity, and sport can strongly override any differences due to disability and the barriers that normally exist are eliminated.

Theories of Adoption of Physical Activity

Certainly, for many other disciplines, society is not the prime focus and there is an emphasis on the role of individual attitudes and beliefs in determining behavior. Many researchers, particularly as revealed in the psychological literature, have studied the individual's influence on the adoption of physical activity. A recent review of the psychological literature by Marcus and colleagues⁷⁹ examined a plethora of psychological models and theories that have been developed to explain factors that increase the likelihood of an individual to become involved in physical activity. No less than ten separate theories were presented in an attempt to explain the very complex human behavior surrounding the adoption of physical activity. What is abundantly clear from a review of these psychological theories is that societal factors cannot completely account for the likelihood of an individual becoming physically active, there are a number of cognitive processes that also come into play.

A number of theories reviewed by Marcus and colleagues⁷⁹, such as the Health Belief Model, placed the emphasis on an individual's beliefs about physical fitness and the impact that these beliefs can have. From this point of view, the individual's perceived susceptibility to health problems, their perceived impact of those health problems, and their belief that adopting a healthy lifestyle

will be beneficial are among the health beliefs that act to determine their exercise behavior.⁷⁹ The Theory of Reasoned Action, as reviewed by Marcus and colleagues⁷⁹ is somewhat different in that it proposes that an individual's intention to perform a target behavior will predict whether that behavior is actually performed. The intention is comprised of two factors; the individual's attitude towards the behavior and the social factors toward engaging in that behavior.⁸⁰

Another notable psychological theory utilized to explain the initiation of physical activity is Social Cognitive Theory. Social Cognitive Theory proposes that behavior has multiple determinants that include biological variables, psychological variables, and external social and environmental variables.⁸¹ With social cognitive theory, there is a recognition that many variables from all areas, both within and outside, interact and that changes in the individual and/or the environment can affect the individual's behavior. There is also a significant recognition that the individual plays a large role in controlling his/her behavior.

One theory that perhaps best combines the concepts of the psychological theories described above is the Theory of Planned Behavior, described by Courneya and Friedenreich.⁸² In the Theory of Planned Behavior, the principal determinant of a behavior is intent; that is, the individuals' intent to perform that behavior. Intent is determined by the three independent variables: attitude, subjective norm and perceived behavioral control. Attitude relates to the positive or negative feeling about the behavior; subjective norm refers to the social pressure to perform or not perform the behavior; and perceived behavioral control accounts for the perceived ease or difficulty one would have performing

the behavior. Simplified, this theory reasons that an individual will perform a behavior, such as exercise, when they feel positive about doing it, believe that others also feel it is important and perceive that it is under their control.

It is remarkable that despite the numerous theories that have been developed to explain exercise adoption, such as those above, there are very few studies reported in the literature to corroborate them. After a search of Medline documents published over a period of thirty years, Dunn reported finding only two prospective studies that addressed the factors that were important to adopting vigorous physical activity in adults.⁸¹ These studies were both carried out by Sallis and colleagues^{83, 84}. The more comprehensive of the two studies by Sallis and colleagues looked at predicting the adoption of physical activity using Social Cognitive Theory.⁸³ As described above, Social Cognitive Theory takes into account that behavior has multiple determinants including biological, psychological, environmental, and social variables.⁷⁹ In this study Sallis and colleagues, found that for both men and women, self-efficacy and physical activity history were significant predictors. For men, age and neighborhood environment also predicted exercise adoption. For women, years of education as well as the degree of support by family and friends were significant determinants.

There are a number of points that can be drawn from the above study that are relevant to this thesis. Firstly, as suggested by the social model of disability, it is apparent in the study by Sallis and colleagues that both the physical environment and society play a significant role in the likelihood of an individual becoming physically active. Yet the results gathered by Sallis and colleagues

confirm that an individual's beliefs and physical status can also play a large role. Furthermore, the results of the study by Sallis and colleagues demonstrate that there is a notable difference in the factors predicting exercise adoption between men and women. If gender can create such differences, it follows that factors significant to those with SCI must also be unique. Just as issues are different for men and women, they are likely to be different for those with SCI when compared to the general population. It is because of this reasoning that previous studies examining the initiation and incorporation of physical fitness into an individual's lifestyle in the general public must be viewed with caution when similarly examining the population of individuals with SCI. The issues and concerns of the general public and the SCI population are likely very different.

In the same Medline review that produced the dismally scarce amount of prospective studies examining the adoption of exercise, Dunn ⁸¹ reported that a search of the literature found over two hundred studies examining barriers to physical activity. Despite this apparently large body of literature on barriers, these studies are of limited use when looking at the issues faced by those with SCI. It is certain that just as the issues surrounding exercise adoption are likely very different for individuals with SCI, the barriers to physical activity are also unique.

Summary of Theoretical Literature

The review of the theoretical literature has illuminated a number of significant points. Primarily, that the social model of disability provides a sound theoretical framework from which to understand the issues surrounding disability.

When a consideration of individual influences on disability, such as impairment, is allied with the social model a comprehensive viewpoint results. As well, despite a number of theories, there are very few prospective studies examining exercise adoption in the general population, and none known for those with SCI. The studies that do exist, although providing a starting point, are likely of limited application to the SCI population. There are many more reported studies in the literature examining barriers to exercise and physical activity in the general public, yet again the degree to which these can be applied to the SCI population is unclear and likely limited. There have been studies examining the barriers to physical activity in the SCI population. Unfortunately the issues are often indirectly addressed and, as in the recent study by Rimmer and colleagues⁵³ specifically examining barriers to exercise in African American women with disabilities, the list of potential barriers are often selected by the researcher and not by those with SCI. Previous to this thesis, no study had examined the issues of physical activity after SCI employing a qualitative framework, utilizing the perspective of the social model of disability.

In this study, the social model of disability provided the central perspective through which the research questions were constructed. This allowed for a unique and meaningful approach to the issues facing individuals with SCI in a way that has not been presented to date in the literature. However, as noted in the above review of the literature, the issues surrounding participation in physical activity after SCI are complex and multi-factorial. It would be unreasonable to conclude that a recognition of the issues from only a social

model point of view would provide complete, or even accurate, conclusions. Therefore, although the social model formed the basis of the approach of the study, there was also due consideration of individual factors as well. An individual's impairments, as noted by Crow ¹², can play a limiting role and were recognized in this study as such. Individual psychological factors, such as beliefs, attitudes, and intentions were accepted as potential influences also.

The Formulation of a Question

The personal story of the development of a research question was outlined in the first chapter. Through my clinical observations, and the shared experience of living with a SCI through my wife, a recognition of the potential benefits of physical activity and sport for individuals with SCI began to develop. My own awareness of the benefits I experience from physical activity, as well as my knowledge, as a physical therapist, of the medical effects of exercise contributed to a growing interest in the situation. After a review of the literature to date, as has been outlined in this chapter, it is apparent that the personal and professional observations that led to this research certainly resonate with the experiences of the individuals with SCI. It is from this initial experience, and the corresponding literature, that the research question developed:

What enables or discourages individuals with SCI from becoming involved in physical activity and sport?

Although a seemingly simple question, the discovery of an answer will likely not be an easy process. In this chapter, the literature addressing this topic

has been reviewed and it has been noted that the issues surrounding the involvement of individuals with SCI in physical activity and sport appear to be multi-factorial and complex, with both societal and individual influences. Certainly, research methods utilized to answer this question must be able to accommodate this complexity. The methods utilized in this study are discussed in the next chapter.

CHAPTER THREE

METHODOLOGY

CHAPTER THREE: METHODOLOGY

Choice of Methodology

As a physical therapist trained in the quantitative paradigm that has historically dominated the research in our profession, qualitative methods were largely an unknown, and under-appreciated, method of gaining knowledge. In attempting to examine the issues faced by individuals after SCI, I struggled with establishing a research design that I felt would derive fruitful data.

Qualitative and quantitative methodologies have been described almost as adversaries, competing in a clash of philosophies.⁸⁵ Yet, it has been pointed out that this philosophical battle is unnecessary, stressing that the choice of research methods should depend upon the question being asked.⁸⁶ Others have noted that researchers need to determine whether the underlying assumptions of quantitative or qualitative research fit better with their particular study.⁸⁷ In this sense there is no longer a need for competition between the two paradigms. They can be viewed as two different methods of answering a question. Some questions are better answered with one method, some with the other, and many questions likely benefit from investigation by both approaches. When I reflected upon the contrasting philosophical pillars upon which qualitative and quantitative methodologies are founded and the goals of this study, the qualitative approach emerged as the methodology of choice.

To date, the vast majority of research in the area of SCI has been quantitative. The quantitative approach has its roots in positivism which is defined by Polit and Hungler ⁸⁸ as

...the process whereby evidence rooted in objective reality
and gathered directly or indirectly through the human senses
is used as a basis for generating knowledge.^{pg18}

With positivism, an underlying assumption is that there is a single, objective reality that can be discovered through testing a hypothesis that reflects an anticipated answer to a question.^{89, 90} The components of the problem are viewed as separate, independent components, as is the influence of the researcher. In rigorous quantitative research, the study is designed in such a way as to control the environment and all variables in order to discover a fundamental law or predict a probable outcome for a defined population. Certainly, science has served humankind well in many respects using this paradigm. We have become highly advanced in many areas, including medicine. Quantitative research in the area of SCI has served us well to date, and certainly beneficial results may arise in the future from "cure" research being conducted currently. Yet, when examining the more complex social world, quantitative methodology cannot provide a complete picture. Critics have claimed that quantitative research "ignores the differences between the natural and the social world by failing to understand the 'meanings' that are brought into social life."^{86 pg.5} It is in this realm that qualitative methods are appropriate.

The basic tenets underlying qualitative research are vastly different than the assumptions of quantitative research. With a qualitative approach, there is recognition that reality is socially constructed. There is not one single objective reality but multiple realities, which are socially constructed by the individual.⁸⁹ Human beings, are complex, unique individuals with many concerns and problems specific to themselves. Defined by Merriam, "the world is not an objective thing out there but a function of personal interaction and perception. It is a highly subjective phenomenon in need of interpreting rather than measuring."⁹¹ Shepard and colleagues⁸⁹ relate that a qualitative paradigm acknowledges that " individuals need to be understood in their entirety within a situational context, not separated from the environments in which they function."

pg. 89 A quantitative study, in which the environment must be controlled, cannot fully discover an individual's experiences. Shepard relates the basis of qualitative research as trying to understand human activity from the perspective of the person being studied.⁸⁹

It was noted above that despite the historical conflict between qualitative and quantitative philosophies, a number of scholars have pointed out that both views can serve as a legitimate and appropriate framework for a study depending upon the question that is being asked ⁸⁶, or whether the underlying assumptions of quantitative or qualitative research fit better with their particular study.⁸⁷ Also of consideration must be the philosophical perspective of the researcher. As noted by Shepard and colleagues⁸⁹,

...if a researcher thinks about the world in terms of complex human behaviors and multiple realities, he or she is more likely to ask

questions that encompass the study of these multiple dimensions.^{pg.90}

When looking at the question I was proposing, it became apparent that a qualitative study was the most appropriate way to address the numerous and complex social issues that were of interest. Furthermore, as the intent was not so much to find definitive answers but to illuminate and discover issues, the qualitative paradigm stood out. Although not consciously aware of it when this process first began, my personal philosophy also complemented the ideals of the qualitative paradigm. With such congruency with the paradigm, it was evident that the chosen methodology was appropriate.

It should be noted at this point that the selection of a qualitative paradigm is in no way an attempt to deem one methodology superior to another. Shepard and colleagues⁸⁹ point out:

...a more profound understanding of a phenomenon comes from the examination of that phenomenon both from the use of different research designs within a single philosophical perspective and from the use of designs typical of alternative philosophical perspectives.^{pg.90}

I concur with these thoughts and emphasize that both methodological approaches can bring about beneficial results. The goal of research, after all is the same regardless of the methodology. As described by Yerxa⁹²:

Research is *not* a particular method or adoption of a particular scientific model such as Newtonian physics. It is, rather, a careful, reasoned search –a scholarly pursuit of understanding. I think of

light related words: lighting a candle, enlightenment, lightening up, illumination that penetrates the darkness of ignorance.^{pg.415}

With this in mind, it is hoped that this study will be the first of a number of studies, both qualitative and quantitative, to examine the issues in this area and serve to shed light where there is currently darkness.

Positionality

Overview

Previously, in the discussion of the divergent viewpoints of qualitative and quantitative research, it was noted that in quantitative research every effort is made to decrease the influence of personal bias of the observer or researcher. This is not so in qualitative research, as with the current study. In qualitative research, it is recognized that the choice of research topic and method itself comes from the interests and choice of the researcher. The researcher's relationships and interactions with participants, as well as the lenses through which he or she views the data have a notable influence on the research. It is accepted that these aspects, as well as gender, class, race, sexuality, age, religion, (dis)ability, and other aspects of social differentiation affect the research relationship and the nature of the data collected.⁷¹ This is referred to as the "position" of the researcher. In order for the reader of the research to evaluate and gain a full understanding of the research the position of the researcher, an inescapable factor in the work, must be fully revealed. As such, it is critical to the

authenticity of the work that the researcher presents their positioning as part of the research.

Positioning can be a contentious issue in qualitative research. When a researcher's positioning is vastly different from those being studied there can be feelings of misrepresentation and misunderstanding. This view was expressed by feminists objecting to the traditional, male dominated research aimed at exploring women's lives.⁹³ However, authors have also found that criticism can be received for being too close to the researched as well, as did Hammell in her dissertation on high spinal cord lesions.⁷¹ This is particularly relevant to me, as I am in just the same position, as the spouse of an individual with SCI. Yet, as can be ascertained from these illustrations of the two extremes, there is no perfect positioning. In fact, assertions that one's positioning is problematic likely result from a positivistic view of a "tainted" sample or of researcher bias. These concepts have no place in qualitative research. However, regardless of where my exact positioning falls, it is still of notable importance and therefore must be presented and reflected upon as it relates to the study.

Biographical Positioning

I was born and raised in Prince George, a relatively small town in central British Columbia. Partly through happenstance and partly, I am certain, due to the remoteness and sometimes harsh climate of Prince George, my exposure to disability through my formative years was limited. If one were in a wheelchair, getting about during the long winters would be quite difficult. Other than the few

classmates with deafness, or cerebral palsy, and relatives with arthritis and stroke, my exposure to disability was minimal. Around the time I was in tenth grade, my exposure to, and interest in, disability expanded rapidly. It was at this time that Rick Hansen, a well know Canadian, was finishing his trip around the world by wheelchair to raise awareness of SCI and to raise funds for SCI research. The nation was engrossed with his travels and his progress was a daily feature in the media. I was heavily involved in cycling at the time and as a member of the local cycling club, was selected to be part of the escort through town when Rick Hansen and his caravan passed through. During a break, I had the pleasure to meet Mr. Hansen, as well as the physiotherapist that was travelling with the tour. My interest in SCI, and particularly physiotherapy was magnified and I began to research it as a profession. Six years later I left the University of Alberta with my degree in physiotherapy.

Through school, and my subsequent work as a physiotherapist, my awareness and experience with disability of all kinds increased significantly. I have worked with a wide variety of clientele, from pediatrics to geriatrics; however, the majority of my career has been spent working in rehabilitation. I have spent most of that time working with persons with SCI and those recovering from cerebral vascular accidents (CVA). It was during these years that I began to notice the difficulties clients were having incorporating activity into their lifestyle after returning to the community. This was particularly true of the younger demographic which comprises the vast majority of individuals with SCI. In addition, I noted that many of the return visits to rehabilitation were due to

secondary complications that often arose from inactivity, or at least would have been less likely to occur had the individual been more active. These 'real life' observations were backed up by the current literature, as was outlined previously in the literature review, and from them my interest in this topic grew.

It is likely however, that this thesis would still not have developed had further events not unfolded in my life. As well, my experience with disability would likely have remained on a professional and clinical level. While working in the United States I met, and later married, my wife. She was injured by a criminal's stray bullet in an unfortunate accident in 1991 and is a T4 paraplegic. Through her, I have shared in the experience of disability as an everyday part of life. We have encountered barriers and frustrations due to her disability, yet at the same time enjoy an extremely full and fulfilling life. This personal side of disability has provided me with a much deeper and richer knowledge of disability than I could achieve professionally, as well as a substantially different viewpoint.

As noted previously, there is often criticism at a researcher being too close to their subjects. The accusation being that one is unable to objectively view the issues. This argument may stand true in the 'traditional' quantitative sciences in which the experimenter is to have as little influence on the results as possible, however fails in the arena of qualitative inquiry. Anthropologists, the area from which modern day qualitative research originates, traditionally went to live with their 'subjects' for extended periods of time in order to become familiar with the culture they are studying. In fact, there are a number of authors who contend that in order to research those with disabilities the researcher must be familiar with

disabilities. Stone and Priestly⁹⁴ report that disability research has attracted significant criticism from individuals with disabilities who contend that it has taken place within an oppressive social environment, particularly when the researcher is able-bodied.⁹⁴ Unequal power relationships and able-bodied researchers being viewed as casting themselves into the role of expert have been viewed to create fragile relationships in disability research.⁹⁴ Barnes contends that a researcher must at least interact with individuals with disabilities on a regular basis in order to have some understanding of disability.⁹⁵

Brooks⁹⁶ outlined a number of advantages gained when a researcher is familiar with a particular impairment. Firstly, the researcher is able to communicate in a shared language consisting of terms unique to that condition and with a full understanding of their meaning. As well, awkwardness is decreased and embarrassment is lessened for participants who may otherwise be highly self-conscious when they discover that the researcher is familiar with and has an understanding of their disability. Brooks further suggests that the researcher with familiarity of an impairment will be less likely to be viewed as a parasite, using the research for self gain.

Indeed, as noted earlier, there is no perfect positioning. However, it seems that with qualitative research an awareness of the subject's situation is certainly of benefit. Regardless of where exactly my positioning lies, the transcript arising from an interview is a product of both the interviewed and myself. I can not be separated from it. My positioning will affect the questions I ask, just as certainly as it has affected my choice of topic and interests. Yet, as with all qualitative

research the goal is still to have the voices of the participants come through the strongest, shedding light on the issues from those in a position to know.

Positionality with regard to physical activity and sport

As physical activity is an important concept in this research, it is important that my positioning concerning physical activity and sport is outlined much in the same way as my biographical history and its relationship with disability has been. As noted earlier, cycling was a large part of my life when I was a teenager. Throughout my formative years, in fact, physical activity and sports played a large role and continue to do so today. I was involved in a number of school and minor league sports as a child and developed an interest in cycling, a sport that would consume me through to my university years. I continue to be involved in physical activity and sport to this day, however in a much less structured way. I became involved in triathlons during my years in university, enjoying the mental and physical challenge as well as the benefits of the accompanying healthy lifestyle. This participation culminated with my participation in a couple of Ironman triathlons, a long distance endurance event. For me, physical activity and sport has evolved from a team and social event to a personal, more meaningful challenge. Today I continue to be active, exercising nearly every day in some way, even if it is just a short swim in the local pool or taking my dog for a long walk; my exercise is not nearly as structured as it once was. Yet, for me it continues to be a fundamental requirement for maintaining balance in my life.

Simply stated, I find that I feel better when I exercise; that is the main reason I continue with it.

It is this personal recognition of the benefits of physical activity, in combination with the observation of a lack of physical activity in individuals with SCI that planted the seeds of this project in my mind. As with any qualitative researcher, therefore, I must ensure that I am cognizant of where I come from to ensure that the voice I allow to come through in the thesis is that of the participants and not my own. However, not to mention my positioning concerning physical activity and sport would be misrepresentative of myself and leave the reader with an incomplete view of my positioning.

It is this background and history that I carried into the interviews that comprise this study, just as those interviewed brought with them their unique background and history. What is important, however, is that our background does not serve to limit our views and prevent us from seeing differently. During these interviews, the input of the participants enhanced my views of disability, physical activity, and sport and allowed a view of the subject I would not have achieved on my own. This is the goal of qualitative research; this is its power.

Research Methods

Overview

The research method chosen to achieve the goals of this study was the in-depth, semi-structured interview. The interview was designed to probe specifically into the issues arising in the participants' lives regarding physical

activity and sport. The basic structure for the interviews was constructed from the review of the literature as well as drawing from my personal experiences and beliefs, yet were open and free flowing to adapt to each subject.^{71, 97} . The loose structure allowed for the interviews to be shaped and developed for each participant depending upon their responses, comments, and thoughts. In this way the interviews were designed to address the same issues, yet encourage individual variation. When topics of particular interest arose, I was able to probe more deeply. In this way, my previous experience with individuals with SCI became an asset, allowing me to recognize and respond to important issues arising during the interview. As well, my personal knowledge of the "inside world" of SCI gained from my wife allowed me to more easily relate to issues specific to this population, facilitating a more free expression of feelings. My extensive experience with physical activity and sport was also beneficial in much the same way, creating a level of recognition and comfort with the discussion.

Along with the interviewing process, a further technique aimed at increasing the richness of knowledge gathered was utilized, described by Hammersley and Atkinson⁸⁵ as "analytic memos." These are notes in which I recorded my inner thoughts and reasoning throughout the study. This process enabled me to reflect upon the issues throughout the study and to "trace the way (the) intellectual process (is) shaping the research design and emergence of themes."¹⁴ I kept a spiral bound notebook on my desk at home, beside the computer and endeavored to frequently record my thoughts and musings. In it, I recorded notes on my thoughts and feelings about each interview and on the

progression of the study. Reflecting back on these notes from time to time allowed me to keep track of the relevant issues I felt were emerging and enabled me to address these issues with future interviews and consider them in my overall analysis of the data. My “analytic memo” notebook also became the location for thoughts on relevant literature, as well as a place to sketch diagrams and flow charts in an attempt to visually organize the emerging data. In summary, it became the place where my thoughts became tangible. An example of an “analytic memo” follows:

Access to equipment appears to be a big hurdle for a number of participants, mainly because of availability and cost. Finances especially come into play here and many sports require specialized equipment. Perhaps equipment could be better, cheaper, and more available but in a capitalist, market driven society no business can make money providing them..... (Analytic memos –Jan16th, 2000)

After each individual interview was completed and transcribed, I scanned over the transcripts. Reading and re-reading them a number of times, I looked for areas in which I felt I had gained meaningful responses as well as the times in which my questioning was misinterpreted or even drew a blank. Reflecting on these times allowed me to re-frame and alter my lines of questioning in later interviews. After a thorough review of each transcript, reflections and comments were included in my analytic memos. In this way, the process was a cyclical and reflective one.

After I had completed the first three interviews, both my graduate supervisor, Dr. Darlene Redenbach and committee member, Dr. Isabel Dyck

reviewed the transcripts. They made helpful suggestions on my interviewing technique. For example, pointing out where I had perhaps not addressed an important topic brought up by the participant and had instead gone to a different line of questioning. Dr. Redenbach had me perform an exercise in which I took all of the topics that I wanted to address and organized them on paper, and thus in my own mind, into some sort of chart. The goal was to organize my questioning in my own head so that I would be more likely to address all relevant issues in subsequent interviews without being constrained to a question list or contrived order. It was a process that I feel was greatly beneficial, as I felt much more comfortable in future interviews.

As the interviews were transcribed and saved in ATLAS-ti®, the data analysis program I chose which will be expounded upon later, I was able to attach memos to small segments of text in order to record specific observations and notes. For example, if a participant sighed while commenting on something, or if I felt that I picked up a relevant tone in their voice I made a note of it and attached it to the specific sentence or quote. As well, I would often note where tone and choice of wording was similar to or markedly contrasted other participants. An example of such a memo, from Beth's interview follows:

Her sighs here are notable and she takes a number of long pauses when answering. These seem to be signs of just how much she really is missing activities such as hiking. She relates this to the physical inability to hike, yet is it also the loss of social aspects? She used to go with her boyfriend.

These specific memos, combined with the more over-arching “analytic memos” noted earlier provided a more three dimensional perspective of the data than simply the text of the transcripts.

Ethical Approval

In compliance with the Ethical Review Policy of the University of British Columbia, ethical approval was applied for through the Office of Research Services and Administration. The Behavioral Research Ethics Board granted approval on June 14, 2000 (Number BO-0244). In order to secure the ability to recruit research subjects from the G.F. Strong Rehabilitation Centre outpatient program, approval was sought from the G.F. Strong Research Advisory and Review Committee. Approval was received on July 14, 2000. (Number 00-1006)

Pilot Study

Prior to the participant recruiting and interviews, a pilot study was undertaken in with an individual with a SCI who was well known to the researcher. An interview was carried out using the planned structure and questions of the later interviews. This interview provided the researcher with an opportunity to become more familiar with the qualitative interview process and to be aware of potential problems with the planned questions. A review of the pilot study transcript and audio tape allowed the researcher to critique their performance and revealed questions that brought forth meaningful responses, as well as questions that were misunderstood or unclear. The process was valuable

and, along with the interviewing skills developed by the researcher as a student, enabled the future interviews to flow more smoothly.

Participant Selection

Inclusion Criteria

The selection of participants for a qualitative study does not require, as its goal, an attempt to obtain a statistical representativeness. Although by no means is there a lack of rigor to the qualitative process. Sampling in qualitative research is neither personal or statistical, but theoretically grounded.⁸⁶ The association between theory and sampling is outlined by Mason:

Theoretical sampling means selecting groups or categories to study on the basis of their relevance to your research questions, your theoretical position...and most importantly the explanation or account which you are developing. Theoretical sampling is concerned with constructing a sample...which is meaningful theoretically, because it builds in certain characteristics or criteria which help to develop and test your theory and explanation.^{98Pg. 93-4}

It was with these thoughts that guidelines for the recruitment of participants were developed. The goal was not to derive a random sample representative of the population for statistical analysis, but a sample whose stories would resonate with the broader SCI population. As such, there were very few criteria established to exclude participants. The guidelines for selection are outlined below, and a summary of the demographics of the participants is included in Appendix I.

Level and completeness of Injury

For the purposes of this study, participants must have had a SCI at or below the level of the first thoracic vertebrae (paraplegia). At the risk of excluding a large number of individuals with SCI, this was considered necessary largely due to the small sample size of the study. The issues arising for those with cervical injuries are likely to be vastly different and perhaps more complex with respect to participation in physical activity and sport. Individuals with cervical injuries often require power mobility and ventilatory support. If the participants were both paraplegic and tetraplegic, it would further subdivide the group and in a sense create two smaller studies. This may have served to diminish the power of the findings and confused the issues and needs of both groups of individuals. Using a more narrowly defined population will provide a framework from which further questions can be developed. Future studies could be undertaken to examine these same issues for those with tetraplegia.

No guidelines were outlined for completeness of injury and participants had both complete and incomplete injuries. Although the majority of participants did have functionally complete injuries (some may have patches of sensation below the level of injury), one individual who responded to the call for participants had a unique injury to the spinal column in which he was functionally complete (although an incomplete injury) at first and then began to get functional return. Considering the questions posed by this study, his testimony was deemed to be just as relevant as those given by individuals with complete injuries as he had experienced the same circumstances as the others and, to some degree

continued to experience the same issues. His unique position was considered to have shed a different light on the issues and served to give a more complete and well-rounded view. This is of particular relevance today when better emergency care leads to a higher percentage of individuals sustaining incomplete than complete injuries.

Regardless of their level and completeness of injury, all participants were required to be free of other health conditions that would preclude them from participating in physical activity or sporting events. If they were unable to participate in any physical activity, their insight into the issues raised by this study would have been of limited use. As participant numbers were relatively low, this would have influenced the study significantly.

Age Range

No particular age limit was set, however participants were to be of the age of consent in order to participate. I wanted to ensure that the opinions gathered were from a diverse group of individuals and recognized that by excluding someone based on their age would be excluding insights and comments that could be valuable to the research.

The majority of participants (5/8, 62.5%) were in their early to mid forties at the time of interview with only two participants younger (ages 24 and 35), and one participant older (age 59). The mean age of participants was 42 years and the median age 42.5. Although this was qualitative research and generalizability was not a specific goal, it was hoped that the findings of this research would be

useful to the SCI population as a whole. Therefore, cognizant of the normal demographics of SCI and its overwhelming tendency to occur in young adults, the more appropriate age to examine to determine the similarity of the study sample to the general population would have been the age of the participants at the time of injury. The mean age of injury for the participants in this study is 25.6 years, and the median age is 21. These figures are congruent to those reported in SCI statistics in the literature.⁹⁹

When considering the nature and objective of this study there was perhaps another figure of a demographic nature to be considered. The core issues addressed by this study relate to the participant's experience. When examining the time since injury, it was evident that there is a considerable range of experience with SCI presented by these participants. The participant injured at age 57 had only been living with the issues of SCI for two years, where as others had five or nine years of experience, and three participants had a considerable twenty seven years pass since their injury. It is evident that the goals of sampling for this study were achieved, resulting in a diverse group of individuals whose experiences will speak to the larger population of individuals with SCI.

Time since Rehabilitation

Participants were required to be at least one year after discharge from rehabilitation. In this way the variances that exist in individual's time in rehabilitation would be accounted for and the year following discharge would give the person a reasonable amount of time to get 'settled' into a routine of some

sort. It has been suggested that one year may be too little time for an individual to become adjusted and establish a stable routine.¹⁰⁰ However, it can be argued that after one year, individuals would at least have had an opportunity to become involved in activity. Furthermore, it was predicted that the majority of participants would be a number of years post injury. This expectation was fulfilled, as only one participant was within 2 years of participating in rehabilitation and, as noted earlier, the majority were decades past their rehabilitative experiences. The mean time since injury was 16 years. Once again, what is notable is that the range observed demonstrates a wide range of participant experience, lending to a fuller account of the issues.

Activity Level

In order to sample the broad range of activity levels expected in any population, no requirements were set as to the participants' level of activity. Both those who were physically active and involved in sport as well as those who were not physically active were sought. In this way, this study had the ability to investigate the various issues surrounding the initiation of physical activity and sport from the point of view of both those who were successful and those who struggle with regaining an active lifestyle.

Gender

The vast majority of individuals with SCI are men.⁹⁹ Due to this unavoidable fact, it was anticipated that recruitment of female participants could

be difficult. I was resolved to include women in the study, again as an attempt to achieve a varied group. As SCI is related to gender, women with SCI face a sort of double minority status. Firstly, as disabled individuals in an able-bodied society and secondly, as women in a largely masculine SCI world. Physical activity and sport can also present significant gender issues. The role of gender in both disability, and in physical activity and sport is discussed in Chapter Four.

In this study, the majority of participants were male. Three of the eight participants were female, representing approximately thirty-eight percent of the group. This is notably greater than the percentage of women in the general SCI population, although it still is a minority and likely does not impact the relevance of the data. In fact, although only through the eyes of three women, this study provides an opportunity to examine gender differences.

Ethnicity

No limitations were set regarding ethnicity, however as it is relevant when examining issues through the social model the ethnicity of the participants must be noted. Seven of the eight participants in this study are white. One participant is black. However, all participants grew up in a similar environment of British Columbia and ethnicity was not seen to play a major role in this study.

Location

As noted above, participants in this study were to be at least one year out of rehabilitation and therefore, living in the community. The environment in a

structured institution such as a rehabilitation centre or nursing home would not have allowed for individual expression of choice with respect to activity. Interviews with individuals in these settings would have therefore not met the goals and aims of this study, to determine constraints on the individual who was capable of choosing an active lifestyle. Originally, the goal was to have all participants originate from the lower mainland (Greater Vancouver Area), however shortly after beginning the study, issues arose that forced reevaluation of this decision. During an early interview, one participant mentioned that one reason he was living in Vancouver was the lack of activities available in the smaller community he came from. Soon thereafter, a potential participant living in a smaller community on Vancouver Island called. It was decided that it would be invaluable to gain a viewpoint from someone in a smaller community, as it was already appearing that geographical location was a potential factor in the incorporation of physical activity into one's life. Aside from this one individual living outside of the lower mainland of British Columbia, the remaining participants all live in the lower mainland of British Columbia. As such, their issues may not reflect the issues faced by those throughout North America, or even the remainder of Canada.

All of the individuals in this study had attended the same rehabilitation center, GF Strong, in Vancouver, British Columbia. This center is well known in British Columbia, and throughout Canada, as a comprehensive and reputable rehabilitation center and is generally the center that all individuals with SCI in British Columbia would attend for rehabilitation. It is noted that their rehabilitation

experience may, therefore, be different than that of others across Canada and the United States, particularly in terms of opportunities for participation in physical activity and sport. Yet at the same time it must be recognized that the participants in this study, although all attended GF Strong, did so at different times. Some participants were in rehabilitation in the early nineteen seventies, when GF Strong was a new facility, and others were there in the late nineteen nineties. During these two decades not only did the physical structure of GF Strong change shape, the rehabilitative process underwent great change as well. Regardless of the specific location and details of their rehabilitation, it is felt that the common experiences of the participants, as well as their unique stories that can serve to shed light on the larger issues affecting the SCI population as a whole.

Recruitment of Participants

Subjects were sought from two different sources in the hopes of recruiting individuals with varied activity levels. "Active" participants were to be recruited from local wheelchair sporting events, and "inactive" participants were to be recruited through the outpatient department of G.F. Strong Rehabilitation Centre. Initial contact was made via a letter outlining the study, which was provided to potential participants by the researcher or by outpatient physical therapists and recreational therapists at G.F. Strong. A sample of this letter is included in Appendix II. It was felt that this was the most appropriate method of approaching potential participants, particularly when done in an informal manner. It provides

little intrusion into the lives of potential participants, while avoiding the appearance of "official coercion" that Hammell ⁷¹ points out can result when a letter is sent from a facility or organization's mailing lists. Some respondents were asked to recommend others they felt would be interested in participating, thereby identifying future participants via a snowball sampling technique. No preference was given to recruiting individuals involved in any particular sport or activity. In this way, the social factors associated with team sports would not become a controlling factor and a richer depiction of issues arising around physical activity and sport participation could be garnered. However, the sporting events that could be attended in order to distribute the letters of invitation was entirely dependent upon the events that were occurring during the time frame in which subject recruitment was undertaken. Unfortunately, this could lead to data arising from a very small, homogeneous group whose insights would be of limited use to the general SCI population. As it turned out, none of the individuals that were provided with letters of invitation at wheelchair sporting events in the community volunteered to take part. All of the participants were recruited via contact from the researcher and therapists at G.F. Strong, and via snowball sampling.

In retrospect the lack of response from participants in sporting events had little effect on assembling a group of volunteers with varied activity levels, as several of the participants reached via other channels were themselves involved in competitive sport. In fact, the participants in this study were involved in a wide

variety of sports and physical activities and there was certainly no emphasis placed on any one sport.

Participants were sought who were physically active as well as those who described themselves as inactive. I felt that this was vitally important in order to prevent the development of an elite sample of sport enthusiasts. The goal of this thesis was not to address only sport but also physical activity, and to do it in such a way as to become relevant to all individuals with SCI. No guidelines were set regarding numbers of individuals to be 'active' or 'inactive', nor were these terms constrained to a formal definition as they were open to individual interpretation. The purpose of seeking participants from two different areas was to assemble a sample encompassing the range of experiences of the SCI population, not to quantify and compare two defined samples.

An initial goal was to recruit five subjects from each source, for a total of ten subjects. However, it is important to note that equal sized groups were neither aimed for nor required. In reality, it was unrealistic to separate individuals into 'active' and 'inactive' labels. The majority of participants were neither completely inactive nor elite athletes, but fell somewhere in between. There was one participant involved in minimal activity and another who had performed at an elite, world-class level. The remainder fell into areas in between, with some participating in regular and varied organized activities and others involved in activities only as recreation. The level of their involvement in organized activities had also varied over time. Consequently, although the procedure did not occur as originally planned, the end goal was achieved. The participants in this study

represented a wide range of individual experience and provided a well rounded, relevant base from which to examine the issues.

The relatively small number of participants raises the question of how one determines the appropriate sample size. Qualitative texts describe that the actual number of participants required for a study will often depend partially upon when the data becomes 'saturated'.¹⁰¹ Data saturation occurs when further interviews fail to introduce new themes and the researcher is confident that their analysis and interpretations are a legitimate reflection of the range of individual experience.¹⁰² It is described as the point at which:

No new themes are emerging: when new stories confirm what is already understood while adding only slight individual variations; and when the researcher has exploited the opportunity to confirm or explicate these themes with as many people as it takes to feel confident in the plausibility and authenticity of subsequent analysis and interpretations. ¹⁰¹pg.6

I therefore set out to interview ten participants, bearing in mind that I may reach a level of saturation and complete the study with a different number. I found, during the cyclical and ongoing analysis process, that by the eighth interview I had reached the point of confidence alluded to above.

Once participants were provided with the letter of invitation, no further discussion or questioning was undertaken unless questions were asked by the potential participant. In this way, I wanted them to have no pressure placed by outside sources, including myself. I was surprised at how I felt almost

uncomfortable about intruding into their lives and paused to reflect upon the criticisms that had been leveled at able-bodied researchers in some of the disability research. I had written in my analytic memos:

It is amazing how bad I feel asking people to participate. (handing out letters) I felt like I was going to give the impression that I was using them or that I was treating them like guinea pigs in an experiment. Issues of control and status were foremost on my mind.

After they were provided with the letter and I had answered any questions they had at the time, they were left to take the letter home and reflect upon their participation. If an individual decided to participate, a telephone number was included on the letter where they could contact my supervisor. Over the telephone, any further questions or concerns were answered and their telephone number taken. I then called the potential individual and discussed with them a time that we could meet to talk. As well, a location for the interview was selected. On a number of occasions, immediately after being given the initial letter of invitation the participant stated that they did not need to think about it and we immediately set up a time, circumventing the extra step of calling my supervisor's office.

It was decided that interviews would take place in the location of the participant's choice in order to ensure their comfort. As a backup, space was available at the University of British Columbia and at GF Strong, however it was felt that the less attached to a large institution the process was, the more relaxed and flowing the dialogue would be. In a few cases, however, the most convenient

location was GF Strong and a small quiet room in the center was used. One individual preferred this location because he often went to the center to lift weights at an accessible fitness center in the facility. A second participant was often at the rehabilitation center because of his employment. Because of their being accustomed to the setting of G.F. Strong, it is unlikely that these participants were negatively impacted by the setting. Another participant was interviewed at his office, and two others were interviewed at a local coffee shop or outdoor patio. It was my hope that interviews not be conducted in the participants home in order to minimize intrusion into their personal space and safeguard their privacy. However in three cases, the interviews were conducted at the participant's residence by their choice. In one instance, the participant lived in a smaller community on Vancouver Island. My unfamiliarity of the community and of potential meeting places, combined with his willingness and invitation to come to his home led to the decision to conduct the interview in his home. In the second instance, I was again invited by the participant. In this case, I had a longstanding professional association with the participant's spouse, with whom I worked, and I deemed that there would be no problem with conducting the interview in their home. In the third case, I was again invited by the participant, who stated that her home was the only place she could think of to meet at a mutually agreeable time. In each case, my goal to have the interviews take place in a location that was comfortable for the participants was achieved.

When meeting the participants, I began by expressing my sincere thanks for their participation and gratitude that they were willing to share their stories

with me. We would generally establish rapport and engage in some friendly conversation in order to increase their comfort level, as well as mine. Often, if the meeting was at a coffee shop or the patio of a restaurant, we purchased a beverage to sip on during the interview. In many cases, further questions about me and my research, how I began the research, what I planned to do with it, and when I expected it to be completed were answered. Many expressed that they felt it was important and beneficial research and stated that they were glad to be a part of it.

After a time of familiarization, I presented the participant with the consent form (Appendix III). I reviewed the information outlined in the consent form and asked if they had any questions. Participants then signed two copies of the consent form, one for themselves and one for my records. I then, confirmed that the participant was agreeable to having the conversation recorded onto audiotape prior to beginning the recorded interview.

The Interview

With the permission of the participant, interviews were audiotaped onto cassette. The conversations were then later transcribed verbatim by myself. In this way a thorough and accurate record of the interaction was kept. The audio recording was kept also in order to allow myself to re-listen to comments and gather further insight from the participant's tone, pauses, and sighs that would be impossible to glean from the hard copy. By transcribing the interviews myself, I was provided with an opportunity to review in detail the entire conversation. I

found that it was an excellent way to reexamine the discussion, and to reflect on not only what the participant said but its content in light of ensuing points, and its emotional qualities. As well, I could reflect upon my own comments and questions. I was able to evaluate the effectiveness of my questions and comments, and see where I perhaps could have changed my approach. I could then keep these observations in mind when approaching subsequent interviews.

The list of issues addressed during each interview was formulated initially from my knowledge of the literature, as well as my previous personal and professional experience. As I proceeded through the series of interviews, I refined my lines of inquiry based on the responses of the participants. If a particular issue appeared to be irrelevant or unimportant to participants I dropped that issue entirely or reformulated the question posed to address the issue. Conversely, when a particular line of inquiry struck a chord with respondents and led to rich, vivid responses, I then explored that issue further in depth. Transcribing and reviewing the text of each interview immediately after it was completed, as well as having some time in between interviews allowed me to adjust my approach in order to gain a deeper understanding. The interviews, therefore, evolved over time with no two interviews being exactly the same. As my understanding and knowledge grew, questions were reformulated or dropped altogether. The interviews ranged in time from fifty minutes to one and a half hours, however most lasted for approximately one hour.

Regardless of the changes noted above, all interviews, whether the very first or the very last, were guided by a core set of issues that came from my

experience both personally and professionally, as well as from the literature. By using a structure such as this, it was possible to provide each participant with an opportunity to address each major issue, yet the participant was given the latitude to respond to each topic in their own manner, with the freedom to elaborate or describe their personal experience.⁷¹ In general, the following questions were addressed:

- ♦ Could you tell me about how you were injured?
- ♦ Could you describe for me a typical day?
- ♦ Could you tell me about your current involvement in sports/physical activities?
- ♦ How do you define physical fitness? How has this definition changed since your injury?
- ♦ Could you tell me about your involvement in sports/physical activities prior to your injury?
- ♦ How has your interest in sports or physical activity changed since your injury, if at all?
- ♦ How has your participation in sports or physical activity changed since your injury, if at all?
- ♦ What motivated you to want to change your activity level?
- ♦ Has your attitude towards physical activity remained the same or changed since your injury? What do you feel are the reasons for this?
- ♦ What, if anything, deters you from physical activities and sports? What things/factors prevent you from participating/ being active?

- ♦ Of the barriers you experienced, which were you able to overcome? How were you able to overcome them?
- ♦ In participating in the activities you do now, how do you get to the facility? Who do you go with? Do you require specialized equipment?
- ♦ For you, what are the benefits and drawbacks to physical activity?
- ♦ How do you feel the expectations of others in terms of your level of physical activity have changed since your injury?
- ♦ Describe your level of satisfaction with your current level of activity.
- ♦ Are you aware of any opportunities for physical activity in your community?
- ♦ Is there anything else you would like to discuss that we have missed?

As mentioned earlier, after the first few interviews had passed, I changed my approach in asking these questions. I decided, upon my reflection and the advice of my supervisor, Dr. Redenbach, that I would be better served to approach the interviews not with a list of specific questions but with an idea of general areas that I wanted to explore. Instead of having a specific list, I kept beside me a chart outlining all of the major topic areas that I wanted to address (for example: activity, barriers). The questions relating to that topic were in my mind and after a few interviews very much committed to memory. An example of this chart is seen in Appendix IV.

In this way, my line of inquiry flowed more freely allowing the participant to take the conversation where they wanted to go rather than being constrained to

my redirecting the conversation to limiting, preconceived questions I chose to ask. There was no intended or implied sequencing to the questions, yet the chart allowed me to check that important areas were covered. This format allowed me get away from having a verbal questionnaire, and towards having a dynamic, interactive, and insightful conversation.

Traditionally, in qualitative research the researcher avoids becoming involved in a conversation with the participant, for example, directly answering questions of the participant or providing personal opinions.¹⁰¹ I was concerned somewhat after reading over the transcripts of my first few interviews and noting a number of areas in which I seemed to be engaging in what I worried would be too much of a conversation. Yet at the same time I felt that my exchanges with the participants were beneficial in a number of ways. Conversing with the participants served to make the interaction more informal and comfortable, and revealed some of my 'insider status'. I felt that it allowed me to fulfill the obligation of qualitative research to probe for the experience of the participant in a free manner, yet sample the areas of interest. It enabled me to get away from the feeling of conducting a questionnaire, with set questions and limited mobility, to move where the conversation went. Some authors ¹⁰³ have challenged the traditional viewpoint, stating that there should be a closer relationship between the interviewer and participant in order to minimize status differences and do away with traditional hierarchical situations. Reinharz ¹⁰⁴ argues that the newer viewpoint provides a greater range of responses as well as greater insight into the perspectives of the participant. I concur with the more recent school of

thought, noting that the allowance of conversational exchanges not only serves to diminish the traditional status differences and place the participant at ease, it also increases the comfort of the researcher. Trust and rapport are created and the results of this are beneficial to all parties involved, leading to what I believe is more insightful data.

There was an instance during the interviews, however, during which I felt as though perhaps the conversation was becoming too large a part of the interaction and we (the participant and myself) were losing sight of the purpose of our discussion. The participant had begun asking a number of questions about my wife, whom she had learned also had a SCI. I realized that all of a sudden I was answering all of the questions and the topic had changed to my wife and her daily routine. I was concerned for a moment and worried over how to address this and return 'back on track', when I realized that the participant was a woman who was struggling with getting involved in her day to day activities again. Her questions were in an attempt to discover information that could help her in her own struggles. As noted by Carpenter ¹⁰¹ in her study examining the quality of life after SCI, I felt that I had a responsibility to provide the participant with the names of resources that could help her with her issues. I would feel very parasitic if I were to leave the interview, taking the information I needed and not giving back to those who offered to share their lives and time with me.

As noted earlier, all interviews were recorded onto audiotape and transcribed shortly thereafter. The process of recording went relatively smoothly, however it was not as elementary a task as I had originally thought it would be.

The majority of the recording difficulties arose from the fact that the interviews were often held in a public location with a number of others near by. Background noise on the cassette tape was often a concern, and I quickly learned that a coffee shop, with its inherent background noise, no matter how few patrons there may be, is not a good place to try and record a conversation and avoided it in subsequent interviews.

Background noise was not the only difficulty dealt with during transcription. At times, with some participants, voices became soft and difficult to hear. Frequently, as is the case with spoken words as opposed to written text, the words of myself and the participant would overlap slightly. On one occasion, the tape twisted and jammed in the recorder. Both the participant and myself were unaware of the technical difficulties for about ten minutes and upon discovery of the problem we played back where we were last recorded and continued there. I am certain that the conversation did not follow word for word the previous ten minutes, however I am also certain that we discussed again all of the issues that were missed by the recorder on the first pass.

Overall the interviewing process went relatively smoothly and despite the above noted minor difficulties, I am certain that essentially every word spoken by the participants was transcribed in the data record.

At the conclusion of each interview, when we were satisfied the topics had been fully discussed, I ensured that participants were given one last opportunity to ask any other questions or add final comments. When they stated that they

were satisfied with the discussion, sincere thanks were offered for their contributions.

Data Analysis

As noted by Hammersley and Atkinson⁸⁵, data analysis in a qualitative study is not an independent and unique stage of the research with a well-defined beginning and end. In fact, it begins with the first word of the first interview and continues through to the writing up of data, occurring concurrently with other stages of the research. Such was the case with this study. As noted by Hammersley and Atkinson, data analysis occurred both formally and informally.⁸⁵ Analysis took place not only concretely, with analytic memos and notes, but also through an iterative process in my own head, with my thoughts and ideas on the conversations with the participants.

After each interview was transcribed, I would read and re-read the transcript, asking myself a number of reflexive questions such as: "What are they saying?", "What did I miss?", "Why do they feel that way?". I wrote down these questions in my analytic memos as well as comments on what I felt the answers would be. I would also write what I felt were the overall messages arising from that particular interview. By undergoing this process after each interview, I was able to reflect on themes to be addressed in a subsequent interview, as well as evaluate areas where I could improve as an interviewer.

Transcripts were then placed into a qualitative data analysis computer program, ATLAS/ti®. This program "allows a researcher to associate codes or

labels to selected segments of text, search these codes for patterns, and construct classifications of codes that reflect testable models of the conceptual structure of the underlying data.”¹⁰⁵ A process described by Hammersley and Atkinson⁸⁵ as “physical sorting” then began. The data (transcripts) were read thoroughly and “codes” were assigned to words, phrases, sentences or paragraphs from the transcripts that illustrated the related code. Eventually, forty-three codes were created. As each interview was coded, these codes were analyzed for emerging “common threads” or themes. When all of the interviews were completed and coded, codes that had commonality, or echoed the sentiments of another code were grouped together under a common theme. For example, some participant’s comments referred to a period of adjustment after their injury, or the difficulty they had calling themselves disabled, or their feelings of self-consciousness. All of these codes really spoke of the process of acceptance and defining a new identity that the participants described, and as such were considered under the broader theme of redefining self.

Utilizing the features of Atlas/ti®, I was then able to print a copy of all of the participant quotes associated with a particular code and therefore, theme. Reviewing these codes allowed me to examine the accuracy of my coding and reflect upon the relevance of the developing themes. A conceptual framework of the developing themes and their interactions was then generated and revised until a suitable interpretation was derived. The common themes that were discovered were integrated to create an overall description of the experiences of

the participants. In this way, it was the developing themes, backed by subject specific quotes, that provided insight into the research question.

Confirmation

Two processes were employed to ensure a degree of rigor was established and that the participants words were indeed being heard. Firstly, after I had reviewed a number of transcripts and assigned codes to passages of text, a copy of the transcript was given to my supervisor, Dr. Redenbach, for her to similarly assign her own codes. This process was completed with three transcripts. A comparison of the codes revealed that, although utilizing slightly different wording similar labels were ascribed to comparable sections of text. Although not identical, the majority of the transcripts were assigned similar codes to those originally assigned.

A further, and perhaps more powerful, process utilized to ensure a degree of rigor was the use of a second conversation with a number of participants. After the initial interview was completed, participants were asked if they were willing to participate in a follow up phone conversation at a later date in which I would confirm with them the issues gathered from their interview transcript. This allowed a method of ensuring that the subject's words were coming through and that my analysis "made sense" to the participant. This process was completed with three participants, Karen, Mark, and Nicole. When contacted, the major themes and overall structure of my analysis was described and any issues

specific to the particular participant addressed. Participants were asked if they felt that my conclusions were an accurate representation of what they felt the issues to be and they were provided an opportunity to comment further on any aspect of the study. All of the participants contacted affirmed the overall structure of the analysis. Karen, when hearing the concept of a redefinition of self and a continual redefining of self stated, "Oh yes. Absolutely." None of the participants had any disagreements with the planned structure of the thesis, and they felt that the analysis "sounds good." With both their approval, and the correlation with Dr. Redenbach's codes, the accuracy and relevance of the data presented is affirmed.

Emerging Themes

When codes were examined, two overarching categories came forth into which all of the codes, and corresponding themes, fell. The codes were described as internal factors or external factors, and the themes derived from these codes were positioned under the appropriate category. The internal themes consisted of data dealing with the internal, personal struggles and views of the participants. The external themes consisted of data relating to the outside world faced by the individuals in this study. The themes are described as such:

Internal Themes

-Identity. This theme derived from data in which participants described their view of themselves prior to and after their injury and how physical activity

and sport, or a lack of activity, influenced this view. As well, issues of gender fell under this theme as gender is an inextricable part of identity.

-Redefining Self. Consists of data in which participants discussed the process through which they adapted to their injury and their new lives. In addition, the process of a changing identity over time and continual redefining of self is included.

-Self Attitudes. This theme consists of data in which participants discussed their views on disability, disabled sport, and adapted activities. The inability to accept the label of disability or adapted activities is an example.

-Meaning of Physical Activity and Sport. Generated from participant's descriptions of the importance of physical activity and sport to them, both physically and in a greater sense.

External Themes

-The body as a barrier. Consists of the participant's accounts of barriers encountered as a result of health problems, or the inability of the body to perform a task, such as hiking.

-The physical environment. This theme is rather large and consisted of a number of codes relating to barriers encountered in the physical environment. As well location, both geographically and in time as it relates to accessibility is included.

-Access means more than curb cuts. This theme represents the numerous quotes by participants in which accessibility other than physical access was

labeled an issue. It includes such areas as resources, access to equipment, time, and finances.

-Attitudes of others. This theme is comprised of data in which participants described the impact, both positive and negative, of other individuals in society. This includes friends and family as well as resources and rehabilitation professionals.

It should be noted that although these themes are presented as a list, no order of importance is implied by the order of presentation. The predominance of themes will be discussed in the following chapters. As well, the themes do not stand alone, but are linked with one another creating an overall representation of the data.

This chapter has focused on the methodological approach taken in this research as well as the specific methods employed to gather data from the individuals participating in this study. Through careful consideration of these data, the words of the participants, themes have been generated that provided insight into the research question through the perspectives of the participants. The division of the themes into internal and external data formed the basis on which the data is presented. Chapter Four addresses the internal struggle faced by participants with SCI and the impact of this process on their participation in physical activity and sport. Chapter Five expands the view outwards, relating the participants experiences, both enabling and disabling with the outside world and

society as a whole. Particular attention to how these societal influences affect participation in physical activity and sport will again be highlighted.

CHAPTER FOUR

THE INTERNAL STRUGGLE

CHAPTER FOUR: THE INTERNAL STRUGGLE

Introduction

It should be noted that it was not the aim of this study to investigate the issues of identity and the process of reestablishing an identity after a SCI. The original intent was to examine the issues affecting individuals with SCI concerning the incorporation of physical activity and sport into their lives. It happened, however, that upon reflection over the words of the participants in this study, the internal struggle with identity and the process of negotiation to redefine self were found to be predominant themes.

A number of qualitative studies have examined the experience of living with a SCI in an attempt to shed light on the impact of such an injury and describe the process through which individuals are going.^{14, 71, 100, 106} These authors all discussed a destabilization of identity with individuals having to undergo a process of "rediscovering self"¹⁴ and the roles that they occupy¹⁰⁶. Carpenter¹⁴ described the process as being comprised of three categories of; rediscovering self, redefining disability, and establishment of a new identity.

Inextricably linked with one's self-identity is physical appearance. Body image plays a major role in how we see ourselves and are seen by others. A great deal of literature has examined this topic and the impact of a disability, such as a SCI, on body image.^{70, 107, 108} It was noted in Chapter Two that society has strong ideals of bodily perfection and the disabled do not fit into this ideal. A

lack of a fully functioning body is a powerful symbol of disability, and often for those with disabilities it is devalued and viewed as a limiting force.⁷³ Therefore, people make assumptions about the physical capabilities of individuals with disabilities based only on appearances. These assumptions and corresponding low expectations could easily lead an individual with a disability to develop a poor self-perception of their own physical competencies.

It was dramatically apparent that the issues of self-identity and the struggle to reestablish a new identity came forth in the transcripts of the individuals in this study. This chapter aims to describe this struggle and to illuminate the role of physical activity and sport in the process. It should be noted here that although the chapter will follow the participants' stories in a chronological sense, there is no attempt to suggest a universal order or theory of adjustment. It is written in this order to provide both an ease of reading and a logical organization of the issues presented.

"Who am I?"

In the time following their injury, participants described a period of time in which they struggled with the loss of an important dimension of their identity. The time period during which this discord lasted varied greatly from participant to participant, yet all related undergoing this to some degree. The loss, or perceived loss, of activities that were meaningful to them appeared to play a large role, as many participants related that physical activity was of substantial importance to them prior to their injuries. Beth reported, " Yeah, I was actually

very active. I did lots of biking, swimming, hiking. I did lots of outdoor stuff, like tennis ... I was pretty active.” She, in fact, related that physical activity was more than a hobby, but more of a way of life saying, “...before my accident I never sat ... I didn’t even sit to watch T.V.. I was always doing something.” For her, physical activity constituted a valuable part of her life, and she placed great value on it, stating “Like if I didn’t go out and do something, I felt like ...I missed it. I felt like I had to do something. Like, I like staying in shape. I like the physical ... how it made me feel.”

Dave certainly had linked his identity to his sport of golf. He related spending a great portion of his time prior to his injury on a golf course or involved with other golf related activities.

Like I’d play maybe twenty rounds of golf a year until I retired. But when I retired, the weekdays I was on the golf course everyday. The weekends I didn’t play because of the crowd. But during the week I was playing everyday.

In fact, for most of his life Dave reported being active, stating that in his younger years before becoming heavily involved with golf, “I was very active. I was doing all kinds of sports.”

The majority of the participants in this study, as with the broader population of individuals with SCI, were injured at a relatively young age and as such activity was an inherent part of their lives and their identity. Grant related,

Well, because I was ... fifteen at the time. I’d been involved in activity... it was my life. Physical activity, ... sport, ... all kinds of sport. Hiking and camping and the outdoor adventure lifestyle was

huge to me and so when I had my accident it was a major threshold to cross in terms of being able to even see whether that possibility existed or not,...

Certainly this focus on activity in the teens and early twenties was echoed by Mark and Nicole, injured at age twenty-two and fourteen respectively. Mark related being "pretty active before my injury", playing baseball, water skiing in the summer and snow skiing in the winter. Nicole was heavily involved with volleyball, playing on her school team throughout the school year and through a summer league in the summer. She noted that she was involved with volleyball most every day and "activity wise, before my accident if I wasn't at volleyball I was on the tramp[oline] for at least, at least, an hour a day." She loved both volleyball and competing on the trampoline and she expressed how much her time doing these activities meant to her, saying "Like I could basically spend half an hour just doing backdrops, like without getting up sort of thing. It was just ... I loved the tramp."

Karen was injured at the even younger age of seven, noting that at that age physical activity is also of prime importance. However, she felt that perhaps at such an age the impact of a SCI did not have as profound an impact on her identity as an active person as it would have at a later age.

I think it's because of the mentality, right? Because kids, no matter ... nothing can bring them down. And so I think that was it. 'Oh well!' And I keep going, right? 'Let's do it this way. Let's do it that way. Let's keep ...' Because playing is all part of being a kid. You just play and that's your focus. Whereas if you are hurt ... , well

people I know that are hurt in their teens or twenties, they go through this big depression or big reflection within themselves.

Karen's observations here are very much supported by other participants comments. It is particularly notable that of all of the participants, Beth and Dave, injured at 37 and 57 years of age respectively, are the two individuals who relate having the most difficult time adjusting to their new situation and returning to either their previous activities, or any activities at all. Details of their difficulties, as well as the issues faced by the other participants will be discussed later, however at this point it is noteworthy that a relationship between age at injury and acceptance emerged. It is likely that the struggles faced in having one's self identity disrupted are magnified for individuals who have a longer period of time prior to their injury during which they more firmly establish their identity.

However, regardless of their age, all of the participants in this study reported experiencing a personal struggle to some degree after their injury. John described experiencing both an uncertainty and a sense of loss of identity, saying, "...you lose that sense of 'Who am I? Is this the way I have to lead my life now?'" Many reported "missing" their previous lives and the activities they were once involved in. Others reported a period of relearning in a sense and coming to grips with their new self. Adam, who's injury was related to a drug overdose, reported that the time after his injury was a time for "huge" changes in his personal and social life.

I had a lot of things to deal with. First of all I had to deal with, you know, um, ... kind of cleaning up my life. I had to get therapy to deal with why I got into using drugs ... to the level that I did. I had a

problem, ... multiple sort of problems that I had for a couple of years after that. So, yeah, I had a lot of things.

Mark reaffirmed the notion that there are many personal and social issues beyond physical activity that must be dealt with after such an injury, stating that one of the major issues for individuals in rehabilitation is “ getting home and getting your life back together again.” Adam relates, “ And you’re just trying to develop ... and you’re just trying to make developments with other people and you are just trying to get back ..., to find out what it’s like to be ..., you know,... .”

Regardless of their specific life situation at the time, the participants in this study related that they all experienced a period of time in which they did very little physical activity. Mark explained, “ after my injury I did very little.” He later elaborated, stating

Well I didn’t do a whole lot actually immediately after my accident. For the first five or six years, um ... I just kind of fell back into the routine of going to work and ... I also ... I don’t think anybody really starts to get use to life in a wheelchair within the first couple of years. Some people obviously adapt better than others. But I think most people tend to take a few years to really get comfortable with what’s happened and kind of come to terms with it. So I didn’t do a whole lot for the first few years.

Adam reported that he definitely underwent a period of time during which physical activity was non-existent, saying, “Yeah, I really wasn’t doing anything. I was inactive for a year or so...” Others reported a period of inactivity that was much shorter, however still profound. Dave stated, “I’d say it was about three or

four months that I would just sit in the chair and not do anything." For Grant, the period of time was also brief, but definite. In discussing his hesitancy in becoming involved in physical activity and sport after his injury he related, " I kept sort of hesitating for a period, not a long period but a pretty decisive period, about whether or not I wanted to do that..."

For some, the struggles of acceptance after their injury were tremendous. Beth reported that she certainly had a difficult time adjusting to her new circumstances, and stated that she is still struggling, to some degree, five and a half years later. She noted that for her, there was a long period of time in which she grappled with acceptance and remained greatly inactive.

[sigh] ... especially for the first four years. I was in a pretty depressed state of mind. Where I just didn't ... I didn't have any interest to do anything, I just ... I sat in my apartment ... really depressed and, um, down and ... I was ... I was just ... I wouldn't leave my place.

She later expanded on her struggles and discussed how being reminded of her former self was difficult for her.

And then after my accident, um ... well I said, I was really depressed. I was just ... I didn't want to go out. I'd go out and that would just depress me more because I'd see people walk. It's terrible. I'd see people walk ... I just ... I didn't take this very well.

She expressed a great deal of difficulty in accepting the new limitations placed upon her body and believing that her new identity as an individual with a

disability was as valid as her previous able bodied identity, of which she was reminded by others.

John also related passing through an extremely difficult time after his injury. As with Beth, significant portions of his difficulties were tied in with the dramatic loss of identity. John was injured nine years ago, at the age of thirty-three, while working as a bouncer for a nightclub. Until that point in his life, a great portion of his identity revolved around very masculine ideals of physical strength and toughness. He reported that growing up he was athletic, but "more athletic in the way of learning how to fight. Boxing and tae kwon do..." The major sporting activities he participated in "centered around being a fighter." He stated that he built up quite a reputation as a tough individual and related it to his work as a bouncer, saying "I had built up a ... name of being someone not to mess with in front of a door or ... trying to sell drugs or anything in front of a nightclub." Working as a bouncer, he kept himself in good physical shape, going to gymnasiums daily to lift weights and maintaining his involvement in tae kwon do. His pre injury identity, therefore, centered around physical strength and toughness. After being shot by a young man he was barring from a nightclub and sustaining his injury, John related having a "very tough" time adjusting to his new self. Ironically, after building up a reputation as an individual fighting to keep drugs away from his nightclubs, John turned to drugs after his injury.

I guess eventually what happened was ... I started swinging to the drug scene. I got involved with heroin, cocaine, ... you know all the ... I dabbled in drugs before my injury and then after my injury I

dabbled a little deeper. Using syringes ... um, shooting up heroin speedballs, the whole works. The whole nine yards.

His lapse into the drug scene lasted for three to four years, developing to the point where John himself became a drug dealer.

When listening to the stories told by these individuals, the profound impact of a SCI on an individual's identity shines through. Each individual relayed narratives describing how their injury served to shatter their conception of themselves. However, their stories do not end there. All of the participants, albeit some sooner than others, reached another stage during which they described moving beyond this period of inactivity and attempting to reestablish a sense of self.

Redefining Self

Several of the participants expressed that, although experiencing a period of time during which they "did nothing", they reached a point at which they decided that they had to change. For John, there was a dramatic moment at which he realized that he was unhappy with himself and who he had become. He described how he became aware of how both his views of himself and others views of who he was had changed in negative ways. He had begun to identify himself as a "junkie" and an addict and that identity was unsettling.

Um ... I took a good look at myself and didn't like who I was anymore. I didn't like being a drug addict, I didn't like ... (sigh) I guess I missed the part where people looked at you and you could see their admiration in their ... , you know, ... just the way they felt

about you. And then, when anybody saw me, even my kids, it was like: "Hi. Bye. See ya when you get off your next high." It was just, you know, a very shallow life to live. And I woke up once, ... before my drug use was ending and I guess what brought it to an end was waking up New Years, um, day before Christmas. Not New Years. Um, ... Christmas eve. And watching some girl walk out with my five hundred dollar Sony 14" screen TV to get more drugs and leave my chair out on the balcony so I couldn't stop her. And that was it. My dog and me were sitting in my room and I called my Mom to get an ambulance and get me out of here. ... I just said I had enough. I want to live. I don't want to live like this. I don't want to be a junkie. I don't want to be an addict. I don't want to leave this planet thinking that I threw it all away because I couldn't deal with being shot and all that stuff. So I said I'm going to change my life. I don't care what it takes. I'm not going to live like this and be a drug addict.

When John no longer saw himself as a Dad, but as an addict the realization that he had become someone he did not want to be finally pushed him to the point of changing his life.

Although not as dramatic as John, other participants noted how they had also come to a point where they did not like who they had become. Dave reported that after spending a few months "vegetating", he recognized that he had changed for the worse, saying " I just ... I would just go from the bed to the shower to the front of the computer to the front of the television ... that kind of stuff. And it's just ... it's just not me." Beth, who was still going through the process of trying to reincorporate physical activity in her life, expressed dissatisfaction with herself in regard to physical fitness stating, "I don't like that ...

I wasn't like that before." She related that she has just recently come to the point of wanting to change who she had become, particularly concerning physical activity.

For Adam and Mark, there was not an epiphany of sorts as with some of the others, although they expressed going through a period of self-evaluation. Adam explained, "I just sort of tried to ... tried to evaluate, sort of, what ... what in my life am I missing? Tried to sort of judge for myself what activities ... what else ... would give me more." Mark related his opinion that individuals with SCI need to pass through an evaluative process such as this after their injury in which they define who they are and what they can and will do.

I think the time it takes to accept the injury and accept what is going to happen ... what changes it's going to make in your life and then realizing what things it is not going to change. The things you are going to do regardless of the wheelchair or whatever.

Adam reaffirmed this idea, noting that he came to a point at which he saw that he could maintain his identity despite the injury, saying,

You know, ... I mean you don't change and just because you are in a wheelchair it doesn't mean that you become a different person. ... you don't change...

This redefinition of self is certainly not an easy process. Six of the eight participants in this study related having significant difficulty accepting their identity as an individual with a disability. Dave, whose injury is unique from the other participants in that it is incomplete, is relatively newly injured and has been experiencing some functional return. Due to this, he has been very focused on

trying to return to ambulatory status and he notes that he is reluctant to accept falling short of this goal. He fought the installation of hand controls in his car, opting instead for having his wife drive him around town, because he did not want the label of 'disabled driver' on his license.

...it took me a long time to get hand controls in the car. I finally did it last year. After about a year without it, in fact more than a year without it. Because I expected my legs to come back. I didn't want to get the ... endorsement on my license to drive with only hand controls. Because I used to work ... in drivers licensing at one time and I know how difficult it is to get endorsements off of licenses. What hoops you have to go through. So I didn't want it there.

He also noted that there "really wasn't anything anybody could do about it. It was my own internal barrier."

Beth did not relate such an overt aversion to the label of disabled, however through her conversation appeared to avoid using the word. When discussing the comfort of the presence of other individuals with disabilities at a local fitness facility she stated "...if there had been more people there with ... if there had been other people I would have felt better." When the word 'disability' was used, it was with an awkward tone. In reporting on a program involving kayaking for inpatients at a rehab center she said, " They were going to try that with people that were disabled, ... " quietly adding, " ...or whatever you want to call it." Grant, although completely comfortable with the subject of disability now, related that twenty-seven years previously when he was injured at the age of fifteen he too had difficulty with the concept of disability, saying, "...it kept tripping

me up. I had an archaic perception of disability, you know. I thought people in wheelchairs with a disability were really disabled people. And I had to redefine that in my head ... It was a steep learning curve.”

Other authors have noted similar difficulties in the acceptance of the “disability” label. Gordon and colleagues¹⁰⁹ reported similar actions among women with chronic illness, finding that some women refused to accept aids such as handicapped parking or a cane. The authors felt that actions such as these were, for some a form of denial, or a coping mechanism, or a desire not to use a label that categorizes them in what may be perceived as a stigmatizing descriptor.^{109pg.9}

It is important to note that the participants in this study who related, implicitly and explicitly, that they were having the most difficulty with the process of accepting their disability and redefining themselves are also the two participants with the shortest time since injury. It is likely that the process of acceptance takes some time. Wendy Seymour¹⁰⁷, in her study examining the process of ‘Remaking the body’ after a SCI noted just how difficult a task individuals were faced with,

Rebuilding the embodied self after such a disruption is an extremely difficult task. A person's self-image has been developed over a lifetime in relation to particular social ideas and in terms of a body with certain skills, abilities and appearances. To confront, and to gradually let go of, those aspects of self-identity that now can never be consummated is the most difficult task of rehabilitation. To hang on to the past, though understandable as a protective strategy in the early stages of crisis, is ultimately counterproductive because

it prevents the person from exploring new subjectives that relate to his or her new body, and to the world within which the person will now live. ^{pg.42}

Both Dave and Beth, to some degree, seem to be still hanging on to the past and therefore experiencing more difficulties. However, they may also be much earlier in the process than the other participants. Dave and Beth, two and five and a half years post injury respectively, have had relatively little time when compared with the other participants, most of whom are decades post injury. The other participants have described acceptance and redefining self as a process. As such, it is probable that Beth and Dave are closer to the beginning of this process.

The majority of participants described becoming involved in, and focused on, some sort of activity that kept them occupied after their injury. Whether it was a hobby, school, travel, or work almost every participant related how they focused on something. For those who were young at the time of injury, such as Karen and Nicole, school was of prime importance. They later traveled to distant, and largely inaccessible, locales and returned to work. Adam also reported work as occupying a great deal of his time and he too, spent many months relatively soon after his injury travelling through Europe and the Middle East. Mark reported that he immediately returned to work and focused on that. These activities likely provided the participants as a way of reconnecting with their former lives, developing, or redeveloping a positive self identity. Mark also investigated and then built an accessible motorcycle in order to return to the

hobby he enjoyed previously. Although experiencing resistance from friends and family, as he was injured in a motorcycle accident, he related how it was fundamentally important to him as a way of regaining what had been a large part of his previous identity.

M: Yeah, the motorcycle. With me the whole motorcycle thing was a big issue. When I first wanted to get back and ride a motorcycle again they were really ... there was a lot of people out there who just shook their heads and said 'Why do you want to do that? Just drive a car and be happy you can drive a car.' It's ... that's a hard thing. People ... if you like motorcycling and it's part of your life that just driving a car doesn't cut it. So people either understand that or they don't. If you are a motorcycle enthusiast you understand that, if you're not you're not.

S: So it was part of you before and...

M: Yeah, it was part of what I did before ... um, just because I was injured on a motorcycle, in a motorcycle accident didn't necessarily mean that I all of a sudden dislike motorcycling.

For Mark, who identified as a motorcyclist prior to his injury, it was important that he maintain that dimension of his identity despite the fears of others. For other participants the participation in activities viewed as dangerous by others seemed to be a way of asserting a strong new identity.

Nicole, who along with Mark and Adam had tried parasailing, described how she felt that perhaps she is more willing to do extreme activities since her injury as a way of showing herself and others something that focuses on ability and not disability, saying,

I might have more of an affinity for trying things. Because it might be more proof that you can do it. So it's like 'I want to try it. Just to prove I can do it.'

Adam related that he has continued with trying out extreme and challenging activities and that a week after our interview he was to skydive. Noting that activities such as this have more meaning for him after his injury he stated that he looked at it as a challenge, saying "I've always wanted to do it so I'm just going to go and do it." He explained that he wanted to "try new things, you know, I want to experiment ...and because you really love life, you know, that's why a person does that."

Whether undertaking an extreme activity, like skydiving and parasailing, or focusing on work, school, and former hobbies, these actions may serve the purpose of, as Nicole stated, proving "I can do it." They run counter to the popular belief that disability is equated with the inability to do things. Involvement in physical activity and sport was also found to be a key method by which participants related they were able to reconstruct their identity in a positive way. It is on this aspect of their re-embodiment that the remainder of this chapter will focus.

The Role of Physical Activity and Sport in Redefining Self

For the majority of the participants in this study, physical activity and sport was notably linked to their identity prior to injury. Almost every individual related that physical activity of some sort was linked significantly with the way in which

they viewed themselves. From Beth and Grant's outdoor lifestyle to Dave's daily golf game and Nicole's daily volleyball practices, physical activity and sport played a large role in the daily lives of these individuals, and likely in the formation of their identity. It follows then that physical activity and sport also play a role in the process of redefining self. The participants in this study all spoke of physical activity and sport playing a central role in their lives post injury, although the way in which it played a role was different for each. For some, physical activity and sport were utilized as a way of defining self. The activities themselves were a vehicle through which participants redefined their lives. Others related that physical activity and sport play a vital role in their life post SCI, however it was not the driving force behind their acceptance but an outcome of a rediscovered and reestablished life. For the majority, it is difficult to separate out the role of physical activity in such a black and white sense and the degree to which it served as a vehicle for rediscovery or was an outcome of a new found life was difficult to quantify. However, it is crucial to note that for each and every participant physical activity did play, and continues to play, a significant role in their reestablishing of their life post SCI.

For two of the study participants, sport and increased physical activity became part of a larger attempt to straighten out their lives post injury. Before his injury, Adam had fallen into "rough times" as a teenager. He ended up living on the street and involved in heavy drug use. He described that his involvement in a number of sports and activities after his injury was part of a time when he "basically cleaned up my life." He felt that, although not involved in a great deal of

sport or physical activity prior to his injury, post injury these activities brought with them a new meaning and purpose. His expression of this new appreciation for what physical activity and sport bring to his life is revealed in the following exchange.

A: *Well I think it helps to keep me connected with other people. It helps to ... it helps to sort of frame my life, you know. It helps to sort of give ... to give my life meaning. It helps me to develop a level of competition. It helps me to be competitive in my life as well.*

S: *You like competition...*

A: *Yeah I like that. Not so much against ... not so much competing against other people, but certainly competing against myself. Try to better things done in the past. Better your best times, best games, or whatever.*

S: *setting goals?*

A: *yeah setting goals. It helps me to define where I'm going. It helps me set goals. And um ... it helps me develop a certain level of persistence when I'm doing things as well, you know.*

For Adam, the entry into a physically active lifestyle was part of a number of changes he made in an attempt to rebuild his life drug free. Since his injury he has learned to scuba dive and founded a Scuba club for those with disabilities, as well as become involved in javelin and shot put through a local athletics organization. His efforts in athletics have earned him trips to the provincial summer games over the past number of years. He spends time swimming and lifting weights at a gymnasium, in order to keep in shape. He also reported enjoying sailing, however regrets that he has not maintained his involvement with

it over the past year. Camping and spending time outdoors have become an important part of his summers, with a number of camping trips planned each year. As noted earlier, he also traveled, began working and became involved in other activities such as pottery. In fact, he noted that he is looking at selling his pottery creations in the near future. All of these activities represent a significant change in Adam's life from his pre injury self, and create a very positive self-image. For Adam, physical activity and sport was an essential element of the process of cleaning up his life.

John described a similar situation to Adam in that he struggled with addiction. However, for John the worst of his struggle with drugs was to come after his injury, self admittedly because of his inability to cope with the changes in his life. John was also notably different in terms of the role of physical activity in his life before his injury. For him, physical activity was of significant importance and he was a regular at a local gymnasium. He stated that he has "always been involved in gyms and doing some sort of physical fitness." noting that "it always revolved around fighting, but it kept me in shape." For John, being a bouncer, being fit and strong was of vital importance and also a large part of his identity, noting that his friends "saw me as something strong." Like Adam, John reported that his re entry into physical activity and sport was part of a larger goal of changing his life. For John it was also a goal of regaining a part of his identity that was lost.

J: So I said I'm going to change my life. I don't care what it takes. I'm not going to live like this and be a drug addict.

S: *Yeah, and so part of that change was becoming more physically active, going into sports...*

J: *Yeah!*

For John, the reentry into a physically active life began immediately after his drug habit stopped and the change he underwent, with regards to acceptance of his disability, was dramatic. He reported acquiring a hand bicycle that became an extremely liberating vehicle, both literally and figuratively. He noted that his initial reaction to the bicycle was cool, however his feelings quickly changed.

And I didn't ... I mean I looked at it and thought 'well, that's cool'. And I wouldn't ... it took me a while to get in, but when I got in I couldn't get out of it. I spent probably ... the first day I spent ... I spent almost 24 hours in it. I just took off on it.

The bicycle became a powerful tool through which John described his attitudes towards and acceptance of his disability changing. As well, he noted that the bicycle "really got me into shape" and served as a method of gathering positive attention from others, both relating to his pre injury identity as a strong and well known bouncer.

And I found I got really, really involved in riding a bike, ... like I loved it. It felt so good to be pedaling like this, and having a three wheel bike, and I was getting noticed by a lot of people. And I just realized that that is something I enjoy doing, I felt my independence coming back. I felt like 'Wow! Maybe there is life in a wheelchair.'

The experience he had with the bicycle became the turning point at which his views of his disability, his identity and his potential changed. He recalled realizing,

Maybe there is a lot more I can do than just push myself in a wheelchair. I mean here I am riding a bike and listening to tunes and, you know, people are going by 'Wow. You look really neat in that thing. Where did you get that?'. I just realized then that ... you can live. You can do whatever you want in a wheelchair. You just can't stand up.

John relayed that he loved cycling, noting that he “could sit in it forever and go and go and go.” He built up his time spent cycling, riding “at least five days a week, for three or four hours a day.” He described the transformation that occurred with the hand cycle as a springboard to other activities, like weight lifting and wheelchair racing.

John's description of the freedom he felt when he began cycling was powerful and it signified the impact that physical activity could have on an individual. Mark, who now works with individuals with SCI through his job, noted that he has seen many stories similar to John.

Um, the one thing that I have noticed working kind of within the industry for the last six years, and it really seems to hold true with the young guys that are injured. And I'm talking about guys who are sitting between graduation from high school and getting into a career. Is that a lot of the guys that don't get into wheelchair sports tend to flounder a lot more than the guys that do. They tend to ... they don't get on track as ... back on track as quickly, they tend to ... if the surroundings allow them they tend to slip into alcoholism or

drug abuse. You know, if a lot of their friends were doing that they tend to do that to try and regain acceptance with that group of people. The guys that I see that have gotten into wheelchair sports seem to get more of a direction in their lives. You see a lot of them, they play competitive sports and then they'll go back to school and they'll get a degree and they will find good jobs.

These observations certainly are consistent with the stories of the participants in this study, and particularly parallel the history of John.

Mark's comments also ring true for Grant, although in the opposite fashion. Grant could more accurately be described as the individual who became involved in wheelchair sports soon after rehabilitation and gained more of a direction and purpose in his life. Like other participants in this study, physical activity and an "outdoor adventure lifestyle was huge" to Grant prior to his injury. During his rehabilitation, he found that the standard template of treatment "seemed very mindless and not linked to something practical that was part of who I was." When he found that he was able to incorporate sport into his rehabilitation process, he became much more excited by the process, particularly as it became much more meaningful and relevant to his identity as an active individual. Grant noted that he used sport as a method of rehabilitation.

I was introduced also to physical activity and sport in a wheelchair as a means of rehabilitation. And so, as a matter of fact it was the more dominant area of interest that I had, because it was my nature. And so, some of the physiotherapists or remedial gymnasts, they would have lunchtime volleyball games in a wheelchair and I

found that I was absolutely really excited, I couldn't wait for that to happen. And after hours I would go and shoot basketball hoops in the...other little gym, and even from time to time, ask people to stand me up on a standing board to shoot hoops from the foul line and have someone feed the balls, and then my old badminton partner would come in and hit the bird around and stuff like that. So I continually used sport as a metaphor and a vehicle to start to pursue rehabilitation.

Grant appeared to begin the process of reincorporating physical activity and sport into his life much earlier than most of the participants in this study, however the process was not without difficulty. He also noted experiencing the same issues as others, such as dealing with questions of what it meant to have a disability. He found that these issues hit him profoundly when he had left rehabilitation and returned to his home community, saying “...it’s one thing to use sport as a vehicle for rehabilitation, it’s quite another to get it in your head that sport can become sport again.” He noted that he “had some significant psychological challenges” to change the way he viewed disability. He reported that after a significant period of wrestling with these issues he did eventually, with the help of friends and family, come to accept the new reality he faced and regained the identity of an athlete that he had treasured prior to his injury.

...once I finally figured it out in my head that I could be an athlete again and that it didn't mean that it was any worse or even any better, it was just a different vehicle ... new vehicle. And that if I ... I could release all my baggage of expectations and comparison on peripheral stuff that didn't mean much and stick to the most important stuff, about what was athletics and what was important

about it and how could I be an athlete again and how could wheelchair sport be a vehicle for me and did it provide the opportunity, the richness, the competitiveness, the opportunity in the kind of sports that I wanted to participate.

Grant was not the only participant who experienced increased difficulty upon leaving rehabilitation and returning to the community. In some ways, it was seen as more difficult than the immediate post injury rehabilitation. Although described by some participants as a location in which they spent some of the worst times of their life, the rehabilitation center was also described as a place where they could feel comfortable and safe. Dave remarked that when he was in the rehabilitation center with “a bunch of people ... in chairs” he felt comfortable, adding “everybody’s the same and they all understand what you are going through because they know what they are going through.” Beth noted that she too felt comfortable in rehabilitation but that the community was a different experience, noting “so you felt comfortable [in rehab], that was O.K.. And then you go out in the real world and it’s not, ... you don’t see many people in chairs.” Dave remarked “when you get out into the public it’s, ... um ... it’s a little different.”

Grant noted that despite his initial difficulties when returning to the community, it was sport that allowed him to reshape his views of disability, shedding the self-image of being disabled and allowing him to move forward to challenge obstacles. He described the process of redefining self that occurred, saying,

...wheelchair sport was vital, because it helped me kind of systematically step through ... , sport became the metaphor for the disability piece. I don't think I woke up and said 'I'm a whole person.' when I was sixteen, seventeen trying to deal with a disability. I think I kind of thought about the concept of being an athlete, and saw it as a positive vehicle and then it also helped me stretch out and look at myself whole as a person over time. And so it helped the more complicated emotional adjustment, and ... so that was a tremendous vehicle to build self-esteem, self-confidence, and feel capable as a person. And a disability issue in general became secondary in my life. It became more of a practical inconvenience that I had to deal with on a day to day basis. Not as a determining factor of who I was as a person or how I felt about myself.

Other participants also remarked that they found physical activity and sport provided them with a method of developing a positive identity. Karen, much like Grant, became heavily involved in wheelchair sports after her injury. Throughout her teenage years she was involved in a number of competitive sports, ranging from wheelchair volleyball to track and field events. She remarked that soon after her injury both she and her parents realized that “mentally she needs this. She needs to be active... .” John noted that physical activity provides him with a positive way of channeling his energy and building a positive self-image, saying “I feel much better after the workout. I feel strong, confident, fulfilled that I’ve done something positive.” He noted that “a good attitude comes from finding something physically ... that keeps you physically fit.

And that's sports." In expressing how sports have enabled him to redefine himself and change his life he observed,

Sports play a key role in your life, in staying healthy, ... participating. They call it participaction. You've got to participate to feel better about yourself. If you do not, you don't get to feel better about yourself. You end up being a dope-head, a coke-head, a heroin-head, ... whatever. You give up. And I know that from experience. Because I lived it.

It is apparent from the stories of the participants in this study that physical activity and sport can play a vital role in the acceptance of a SCI and the formulation of a positive self-identity. However, it is also clear that physical activity and sport are not the only vehicles through which this process can occur. Karen noted that while she agreed that physical activity and sport were beneficial in that it helped you "get moving to prove what you can do with your body", she felt that there were other things that could serve the same purpose, such as school, a career, or a hobby. Nicole, who was injured at the age of fourteen is an example of someone who used another forum to reestablish a positive identity. She noted that after her injury, "my focus was school" and she returned to classes two days after being released from rehabilitation. Mark was similar, noting that "there was no real downtime between my rehab and going back to work, so I really didn't get involved in any sports. Just went back to work."

For both of these individuals, school and work provided another means of reconnecting with their previous life and reestablishing themselves in a meaningful way. It is important to note, however, that although physical activity

and sport was not the impetus for a reestablishing of identity for these participants, it played a significant role for both. Nicole returned almost immediately to recreational sporting activities, such as swimming and wheeling around the local pathways. She gradually incorporated more activity into her life, purchasing a hand-cycle, and trying numerous sports and activities including water-skiing and kayaking. Mark also began becoming involved in physical activity and sport, although not as quickly as Nicole. He began by wheeling around his local area in his chair and eventually became involved in wheelchair basketball, an activity he maintains involvement with today. He also purchased a hand-cycle, which allows him to exercise with his family when they ride bicycles.

The stories told by Nicole and Mark demonstrate that even if not the driving force behind an individual's attempts at reestablishing a positive identity after a SCI, physical activity and sport certainly can provide a positive contribution. For some of the participants, sport was utilized as the primary vehicle through which they formed a positive identity, for others it was one of a number of positive changes in their lives, or perhaps even the outcome of a rediscovered and reestablished self. For some participants, physical activity and sport was turned to immediately after their injury and for others it developed years after their injury. Adam noted that he went through a process after his injury where he had to stop and reevaluate his life, saying that he asked himself "What am I missing?" It was after some consideration and reflection that physical activity and sport became a core part of his life. Beth, who is now five and a half years after her injury is perhaps just reaching this same point. She notes that

sport and particularly outdoor activities were a large part of her life prior to her injury and she misses that lifestyle very much. She admittedly has struggled with acceptance of her injury and reports that she was "very depressed" and does very little activity. She noted that more recently this is changing and stated that, "in this past year ... I've wanted to do some more physical activity." She noted that "I'm getting out more than I ever did" and during the interview asked a number of questions of the researcher regarding activities in the community. She asked one time, "I wonder if there are any sports for me ... or activities...?" Although physical activity and sport is currently absent from her daily routine, it appears that Beth may be experiencing a similar reflexive process as that described by other participants in this study. In her journey of rediscovering and reestablishing self, Beth may still find physical activity as a vehicle by which she may achieve her goals.

For the majority of participants, physical activity and sport were described as a method of gaining acceptance of disability and establishing a positive identity. For one participant in this study, although of substantial importance in his life, physical activity is perceived as a tool in attempting to overcome disability. Dave's injury, as noted earlier, is incomplete and as such he was experiencing some return of function in his legs. He is able to ambulate indoors with a walker for short distances, but has a wheelchair for longer distances and outdoors. Prior to his injury, his lifestyle revolved around golf and he reported spending nearly everyday involved with the sport in some way. He noted that his only goal at the time was to return to golf. Like Beth, he described some difficulty

with accepting his disability, saying "I ... I can't imagine spending the rest of my life in a wheelchair. I just couldn't. I just couldn't." He spoke of the distaste he held for his wheelchair, saying "...it's daunting when you first look at the damn thing and you think you are going to spend the rest of your life in it."

For Dave, physical activity and sport have become tools for improving his conditioning in the hopes of overcoming his disability and returning to the sport he loves. He spends six days each week in the gymnasium or the pool working on strengthening exercises. He is therefore using it as a method of trying to regain his identity as a golfer. He does stand out from the other participants in his struggle with disability. However, it is of importance that Dave is only two years post injury, and he is the oldest participant at age fifty-nine. He has had a much longer life in which to establish his identity and a shorter period of time by which to challenge and reestablish a new identity. As well, the incompleteness of his injury and the uncertainty of the level at which his physical abilities will settle place Dave in a different situation than the other participants. It is clear, however, that just as with many of the other participants, physical activity and sport play a vital role in helping Dave focus his energy in a positive way. Dave does report that he feels that if his injury were complete he would still incorporate physical activity into his life, noting how important it would be to him to continue to be active. He has also investigated using an adapted golf cart that enables individuals with SCI to play, with some modifications. He concedes that although "I don't want to do anything ... too much with things adapted..." he "would have to

force [him]self to do things, like the adapted cart..." as being active is too important to stop.

Physical Benefits ... or much more?

As was discussed in Chapter Two, there has been a great deal of literature describing the importance of physical activity and sport to an individual with SCI concerning their physical well being. The participants in this study affirmed that literature, describing the numerous physical benefits they felt came from being physically active as well as the pitfalls of inactivity. Beth noted that her lack of physical activity over recent years was beginning to have an effect on her body physiologically. She is particularly troubled about this development in view of her previous lifestyle, and remarks that this, at least in part, is motivating her to change.

I need to do something. I know, ... because I just feel ... I don't feel physically, I don't feel ... um ...[sigh] ... very good. Like I did before. I know I'm out of shape, just cardio I'm out of shape. If I do any kind of strenuous wheeling of some kind I'm [huffing and puffing]. And I don't like that because I wasn't like that before.

At the opposite end of the spectrum, a number of participants raved over the physical gains from activity. Adam felt that he received numerous benefits from physical activity, remarking

Well, I just think ... um I just find that when I am physically active I am much less prone to health problems ... I just feel better. I feel better when I get up in the morning ... I have more strength, I have

less worry about injuring myself ... um ... basically ... um ... as far as I'm concerned ... frequency is ... there are far more frequent problems with infections ... bladder infections, kidney problems if you're [not active]. ... Yeah. I think generally you are just a lot healthier. Just healthier generally...

Dave expressed that there were significant physical benefits to his exercise program, noting that he was getting “a good return in strength” and that he was definitely “getting stronger.” John also related that he was gaining strength from his activities and was generally getting “in shape.” Dave relayed that he “enjoy[ed] the ‘physicalness’ of it ... the sweat ... the workout ... the feeling tired at the end of it and watching the progress.” The physicality was important to him, as was the ability to physically progress. John reiterated this need for physical exercise, remarking “You gotta do it. If you are physical, you need to be physical.”

Yet despite these comments, the focus of every participant in this study was not on the basic physical and physiological gains of exercise. It is certainly clear when listening to the participants in this study that physical activity and sport hold a greater meaning to them than just the activities themselves or the potential fitness benefits. For Adam it was described as a way to “frame my life” and to “give my life meaning.” Dave emphatically stated that his exercise was crucial to his life, adding, “I wouldn’t miss [a session at the gym]. I just ... I just wouldn’t miss it.” John described his discovery of hand cycling as an epiphany of sorts during which he realized “there is life in a wheelchair.” Karen described how

much she “loved” being active and how she wanted to keep physical activity as an important component of her life. Adam described the benefits of outdoor activities such as kayaking that for him go far beyond the physical aspects of activity.

...you get away from the noise and traffic in the city and you get a chance to be contemplative and really think. I think it has a spiritual ... it's almost like a spiritual element to certain activities like that. You kind of feel like you are at one with nature or ... at one with God...

Karen described the profound meaning that being able to participate in a hike with her family held. It enabled her to take part in an activity that she was missing, through the use of a specialized chair.

... it's always worked so that when [her husband] and [her son] go I have a day to myself. That is great too, I need that. But I was missing it. They could come home with as many pictures as they want but I wasn't there. I wasn't in on all the conversations, you know. At this trip ... everybody knew everybody and I was privy to everything. Everything that [her son] said and did and, you know, got to see some great moments of them walking together and [her son] walking with me...

She remarked that not only was the social aspect and ability to participate with her family important, but so too was the time she spent alone with nature, remarking,

it was an awesome trip, and you know, I got to sit in a field of daisies which was one of my dreams, you know ... and sit by myself. I made everybody else go...

Unquestionably physical activity and sport hold a deep meaning for many individuals after SCI that goes far beyond the physicality of the activity itself. Grant noted that for him, physical fitness is about more than being physically fit. He described this expanded view of physical fitness.

...I just think that physical fitness is ... you know, there's no sort of arbitrary line there, it's a stated intent based on personal value. And the intent is that one can become comfortable with one's body and aware and capable with ones body so that they can maintain long term health and feel physical and emotional, and perhaps spiritual, ... you know ... sort of ... continuity. Because if the physical fitness is a reflection of value then it probably isn't just about being physically fit. It's a complete loop.

Redefining of Self: An ongoing Process

Much of this chapter has revolved around the issues of identity arising after sustaining a life altering injury such as a SCI, and the role of physical activity and sport in the process of developing or reestablishing a positive identity. It is clear that an identity as a physically active individual or an athlete can be a positive one, with a focus on healthy, life affirming goals. However, it must be noted, as it was by the participants in this study, that an individual is not one-dimensional and there are a number of other ways to develop a positive and healthy self-identity. As, well our lives are not stagnant and our focuses change as years pass by. These unalterable facts must also be addressed.

A number of individuals noted that physical activity and sport were not the only positive aspects of an individual's life, however they did help an individual to focus on other aspects of their life. Mark, who had through work observed many individuals with SCI go through rehabilitation, noted that individuals who began by focusing on physical activity and sport often went on to other positive endeavors, after building their self esteem and an affirmative view of themselves. Their identity did not remain as an athlete, however athletics was an essential component of getting them to the level of success they were at. He remarked,

Even if they don't continue with the sports. It seems that it gets them more focused on things and it gives them something ... it helps them, ... I think, ... set goals for themselves, you know. I mean ' I'm going to play basketball. I'm going to get ... really good at basketball.' And then if they reach that goal then they start to see other goals they can reach, like going back to school and getting a good education, and I mean, really for people in wheelchairs and for most people with disabilities I think an education is the key to getting a good job.

Grant agreed with this concept of a positive spread of the self-esteem gained from sport into other areas of life. He noted that thinking of himself as an athlete helped him to "look at myself as a whole person over time" and see other roles and opportunities. He felt that the positive way in which he viewed himself as an athlete affected other aspects of his life, reporting that "it started to rub off on the way I saw myself as a student, as a friend, and ... you know, as a person." The potential for a positive spread of the gains from physical activity into other

areas of one's life appears to be one of the most beneficial rewards of physical activity.

All of the participants in this study identified a number of areas in their life that were completely unrelated to physical activity and sport that were of great importance to them, and most noted that as their lives have changed their identity has changed also. When asked by the researcher if there was a continual redefining of self through time Karen responded with an emphatic "Absolutely!" She related that her identity has undergone many changes throughout her life. In her teenage years she identified as an athlete, being involved in numerous sports and traveling to competitions. A tremendous amount of her time and energy was spent training. However, as she grew older she found she had a change in her focus. For her, school and boyfriends grew in importance. Then travel and work became a priority. In her adult life her identity underwent a major change as she became a mother, and again as she became heavily involved as an advocate for Mothers Against Drunk Driving (MADD). Her identity changed as the years past and she underwent a continual redefinition of who she was and what was important to her. Throughout her entire life, she reported that physical activity was always of prime importance to her, however she notes that the meaning of physical activity changed over time. When she was young, competition was the focus of her physical endeavors. As she aged the activities became fitness based and primarily for recreation. As she became a wife and mother, her physical activity became a method of spending time with her family. Consequently,

although physical activity remained a core value, the meaning of it and the focus on it changed with time.

A number of other participants also reported undergoing a change in focus over the years. Grant relates a similar story to Karen, describing how his activities and focus changed over time:

I think I went through, in my younger years, an experiential kind of phase and I participated in lots of sports because I loved them all, I was interested in them all. But the competitive part of me realized that if I wanted to go as far as I could in a competitive environment I had to focus and pick one. And so I picked wheelchair marathoning and that was my sport. I dropped all the other sports and focused and gave everything I could to that sport and it allowed me to exercise my excellence and realize all my competitive hopes and dreams. And I look back on it and think that I had a great journey in sport on the development level. I was able to focus in a very specific and elite way. And then I backed up and then started to participate in a number of sports again, for recreation. And now I participate in, not sport, but in fitness, and health and lifestyle.

Mark also found that his activities changed as he had a family and grew older. Although physical activity remained important to him, the means by which he would be active changed. Describing this change, he explained “as of the last few years hand cycling has become what we do as a family now that the kids are old enough and have bikes.” He expanded on the change in activity level, commenting that “it is very much recreational. I don’t race anybody, it’s just something to do.” Karen to finds that, although keeping physical activity as an important part of her life, she does not have the same focus as she once had as

a competitor, saying "I'm past all that psyching people out and that kind of edge attitude. I'm doing this just because I can."

It is apparent from the comments made by participants in this study that participation in physical activity and sport is not stagnant throughout one's life. The amount and focus of their involvement has wavered and changed throughout their life, often reflecting major changes in their self identity. As they changed from primarily being an athlete, to a student or employee, or a parent and spouse their involvement in activities as well as the meaning of activities changed significantly. Reflecting on a time in his life during which his focus changed, Grant described this process:

For a while I was caught up where fitness was a byproduct of my endeavor. So when I stopped my endeavor, like when I changed my direction in sport where it was no longer a priority, my fitness suffered dramatically. What I had to do is hold the phone and recognize that the core philosophy that I had, but had never had to really worry about had to be identified and elevated as a fundamental objective, and that was to be healthy, to lead an active lifestyle. And then I had to elevate that priority to protect it against the way the world functioned and collapsed that time and then I had to commit to things that were important to me. Fishing, and going out in the environment, and being able to have my regular workouts, and get time to spend time with my kids in an active way.

The individuals participating in this study clearly demonstrated that they underwent a constant redefinition of their identity and the degree and meaning of

their involvement in physical activity and sport. Often it seemed the two were linked, with the type and extent of physical activity changing as the individual developed into a new role, such as that of mother or spouse. Regardless of the extent of an individual's involvement and their particular roles, however, all participants reported that they experienced constant reevaluation and redefinition of themselves and their activities.

Gender: A different Experience for Women

One aspect of our identity that we have little control over is our gender. It has been noted that masculinity and femininity are socially constructed¹⁰⁷ and certainly men and women occupy different roles in society. When examining physical activity and sport after a SCI, one is dealing with intensely gendered areas. There is little question that, although changing in recent years, traditionally sport has been largely a masculine endeavor and it plays a large role in male culture. SCI is also largely male dominated, with eighty percent of individuals sustaining a SCI being male. The question therefore arises as to what degree the experience of SCI, particularly as it relates to physical activity and sport, is different for women than men.

Beth wondered if perhaps men were better able to utilize physical activity and sport during rehabilitation in order to "bounce back" faster than she felt she was able. She remarked:

...well I guess it's different for everybody. It is. And I just ... and I don't know how it breaks down ... it would be interesting, obviously there are more spinal cord injured men. And to me I get the

impression that they bounce back quicker. I don't know, maybe not. It seems like they get ... like it happens to them then they get involved in things quicker. I don't know.

She continued, noting that in rehabilitation "it seemed like the guys would just ... they got into things right away."

Nicole observed similar trends in rehabilitation, adding that even when she would want to participate in activities she was reluctant to, as the majority of individuals in rehab were men and their games were too aggressive for her to take part. She expressed her reluctance to participate in the wheelchair basketball games, explaining that:

...you could play it. Yeah. But, I mean there was all these guys and they would ... it looked really painful because they were catching their hands and falling out of chairs and ... it was something that you didn't want to participate in lightly.

For women with SCI that do become involved in competitive sport, gender remains a significant factor, particularly because of the relatively few women with SCI. Karen noted that "there weren't a lot of women to compete with", recalling that often the opportunities for competition were minimal.

I was competing against my own records, I was competing with ... yeah, men on the track, and I was competing with people's records from Quebec. There was a group of people back East that were my class.

Karen could never compete against other women and most often was competing against her own, or other's previous records. A process which provided very little of the social benefit of sporting activity. She noted, in fact, that her solitude played a large role in her decision to stop competing, saying that it "became boring." She "didn't have friends that were into sports" and felt that she was "on [her] own." She noted that the lack of others to train with was paramount, remarking "if I could have trained with a team I think that ... that's a big part of it. The team support."

Inevitably, as reported by the women in this study, the issues facing spinal cord injured women in physical activity and sport are considerably different than those facing men. The propensity of men to incorporate sport into their daily life may lay the groundwork for physical activity and sport to be utilized as a vehicle for rehabilitation to a greater extent than for women. Women historically have typically occupied roles other than that of athlete to define themselves. As well, their identity is less likely linked to sporting activity. Karen's experience outlines how the gender proportions of SCI persons alone creates an uphill battle for those women who see competitive sport as an option for themselves. It is apparent, therefore that although there are a number of 'internal' factors with which an individual struggles after SCI, unalterable and largely socially constructed factors, such as gender also play a role.

This chapter has focused on the 'internal struggle' faced by individuals after a SCI. It has focused in particular on the struggle of rebuilding and

redefining an injured identity and the role of physical activity and sport in this process. It must be noted, however, that one's self identity can not be separated from the society in which it developed and exists. As noted by Seymour¹⁰⁷,

Self-identity is constructed through social relationships. We learn who we are and our place in the world through our relationships with others. Friends, lovers, family, and more distant associates reflect us back to ourselves. They complete the person's self image in a manner that can only be partially fulfilled by the person himself/herself. Pg. 51

Undeniably, we cannot gain a full appreciation of the experiences of the participants in this study by examining only their struggles in isolation of the society in which they exist. There is no question that both the physical and social environment play a large role. It is to this broader world that the discussion will turn in the next chapter.

CHAPTER FIVE

THE REAL WORLD: ENCOUNTERING AND OVERCOMING BARRIERS

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Introduction

In the previous chapter, the discussion focused on issues of self-identity and the struggle to adjust to a SCI, as well the impact of this internal struggle on participation in physical activity and sport. In this chapter the discussion will turn to the more tangible issues related by the men and women in this study. Issues of physical health, physical access, and availability of resources are key, as well as societal attitudes. The impact of each of these issues on the individual's ability to become physically active will be discussed. The chapter will conclude with a recognition that these broader societal issues are also issues of relevance when discussing the internal struggle of the individuals in this study, who themselves are members of the society.

The body as a Barrier

Without question, those with SCI are more prone to secondary conditions that are rare in the general population. Pressure sores, urinary tract infections, and shoulder pain are but a few of the common sequelae of SCI. Some individuals in this study reported the frustrations of these common health concerns. Adam noted that skin problems impeded his ability to participate in physical activities. Recalling a time in which he discontinued his participation in scuba diving he remarked, "it got to be pretty difficult ... um ... I developed some

problems with pressure sores, skin problems ... and so I didn't get involved in it for about a year or so." Beth noted that she hasn't "had a problem with pressure sores", adding that another health concern is primary in her mind, saying, " I do have a problem with one thing, and that's my bladder." Dave echoed her frustration over the decreased freedom associated with planning a bowel and bladder routine.

...although I'm not really on a schedule as such, I have to think about where I am, where we're going and what facilities might be there or might not be there and ... and how long you can hold it. All that kind of stuff. So that's a bit of a barrier.

Other participants noted that health problems can not only be a barrier to physical activity, they can also be a result of it. Karen, who required rods to be surgically placed along her spine to correct a scoliosis, reported numerous incidents during which her participation in physical activity resulted in damage to both the rods and herself, stating, " I had also, during that time in competitive sports, broken my back a couple of times. I had broken my rods, through track, and just overdoing it and all that." She recalled a particular incident during a horseback ride in which, "one of my rods went straight through my hip." She also recalled breaking her ankle during an attempt to water ski. For Karen, these difficulties have compelled her to change the activities in which she participates, although she notes that she continues to remain active, saying, "I just try something else." Grant also noted that at one time he "started to have overuse injuries as a result of neglect." Karen noted that she now tries to find a better

balance in her activities, stating "I go with my limits now. I'm a bit smarter." Although she still experiences pain from her back, she reports seeking activities that are more comfortable for her. Mark felt that by taking a "recreational approach" to his activities he has avoided overuse injuries. Although experiencing some shoulder problems recently, he remarked "I think they are more or less just an age problem."

Recognizing the need for balance, and the potential drawbacks to too aggressively pursuing activity, Grant reflected on his approach.

I'm also learning how to try new techniques to be able to maximize my function and to be able to deal with longer term health issues that typically are associated with disability and aging. When you're young and you're elastic you think you can get away with anything forever and that you're invincible but I've seen role models who have gone there before me and they were quite active and fit and then they ended up having shoulder problems either through sport or because of neglect or ignorance and then they became disabled even more by the time they were late fifties or sixties and so they lived another twenty years of further handicap because their body sort of abandoned them, or they abandoned their body.

However, despite the potential for health problems from activity, participants in this study overwhelmingly felt that the benefits of activity, which were described in the previous chapter, far outweighed the drawbacks. Adam commented that when active "you are just a lot healthier. Just healthier generally."

The Physical Environment

For many, the term 'accessibility' brings to mind an image of a ramp in front of a building to provide access for wheelchairs. It is a concept that the western world has become familiar with and certainly, over the last few decades, accessibility has been increasingly considered by architects and the general population to the point of being defined by the building code. The participants in this study reflected upon accessibility and its impact on their lives and on their ability to participate in physical activity and sport.

The men and women in this study sustained their SCI in vastly different times. For a number of participants, including Adam, Grant, and Karen, the re-entry into society after rehabilitation was almost thirty years ago. Mark completed rehabilitation over two decades ago and for John and Nicole it has been around ten years. Beth and Dave completed their rehabilitation only five and one half and two years ago, respectively. Certainly, the world into which each participant ventured was very different from that in which the others found themselves. Adam remarked that when it comes to accessibility, there have been "major changes from then until now." He recalled, "I remember being in a chair when I was first injured. None of the public buildings, libraries and stuff, and most other buildings were inaccessible." He noted that there were "steps every time you had to go down to the street." Karen, who was also injured twenty-seven years ago, recalled that her hometown "was not set up. It was not wheelchair accessible." She recalled having to have others assist her with curbs, a barrier also familiar to Adam, who recalled "all the curbs have really improved. There wasn't anything

like ramped curbs ... [back then]." Despite their early experiences, these participants now relate that accessibility is "pretty good", and certainly those participants who were injured in more recent years had very little problem with physical access to buildings. However, a number of them did relate difficulties with housing after they were injured. Beth, after waiting in rehabilitation well beyond her planned discharge date, finally moved into housing where she ended up being inconvenienced by a broken down elevator. She ended up having to leave her second floor apartment and lived in a hotel for four months while the elevator was being repaired. She described her frustration with being powerless to affect her situation, recalling

...the first few weeks or whatever it was ... 'This is o.k. ... I can handle this.' Someone else was doing all the cleaning, well ... the aide. I was going to restaurants because they were supplying meals. But after a while it got to be ... it was awful. Like I was after them ... 'When are you going to get the elevators fixed? Come on!'. But a lot of it was legal problems ... the contractors were blaming these people ... it was just terrible...

Other participants also related to Beth's story and noted that accessible housing was an issue for them as well. Nicole recalled living in a number of different houses after leaving rehabilitation until her family found an accessible place. Until they moved she remembered "there were stairs so everyday I'd have to come home and my brother would have to lift me up the stairs." Dave also reported having some difficulties with access, observing "this house is not conducive to a wheelchair."

When it came to incorporating physical activity in their life, or becoming involved in sport, several participants did relate some difficulties. Adam recalled the difficulties he experienced soon after he was injured when he attempted to use a public pool in his community:

I used to do some swimming right after I was injured. And of course there was nothing. There were no lifts there, ... often there were stairs to get into the building where the pool was...

He acknowledged that the building accessibility has certainly improved since then, but noted that he experienced difficulties in accessing a pool even today. Although he can now pass through the front door, he reported a problem he encountered once inside: no ramp or lift is available for him to lower his body into the pool. Adam expressed little frustration with the physical barriers he encountered.

I just jump in. I just throw myself in. I don't worry about that. And then if I want to get out I need to get somebody to just give me a hand and pull me out of the water. I can't get out myself.

The lack of access and the reality that he could not get out of the water on his own did not intimidate Adam. When describing the need to bump down stairs and lower into the pool, he shrugged it off saying, "yeah, you just have to do that to get around stuff. John expressed a similar attitude when asked if he had experienced any problems with accessibility, stating, "No, I just work around that."

Karen also reported an instance in which physical access presented a barrier to her participation in physical activity. When she was in high school, as part of her training for wheelchair sport she would lift weights. However at that time the weight room "was up quite some stairs" and "they had to carry [her] up the stairs to get to the weights." Other than that instance, Karen felt that there were few times in which the physical environment had limited her participation, a feeling that was shared by the majority of the participants. Mark felt that access was "not too bad", adding that "older areas tend to be a little harder because maybe they haven't done the curb cuts yet." He also expressed an attitude similar to Adam and John in that the barriers were regarded as minimal and "there always seems to be a way to get around those things."

Beth also felt that the man made environment was "pretty good" when considering accessibility, however questioned the accessibility of the greater physical environment, noting that a number of her previous physical activities now seemed to be inaccessible to her.

...but I was into ... , like I was going hiking and mountain biking and things like that. I miss that. And I don't know ... can you do that again? I don't know

Mark also noted that the natural environment could provide barriers for outdoor activities observing,

...wheelchairs in general have always almost made it impossible to like, go to the ocean, into the ocean to go swimming, that kind of stuff. Lakes, it's the same thing.

The physical natural environment was also a consideration for Karen when she first returned to her hometown, where snow and ice were common during the winter months. She noted that because she was young she “never really noticed those barriers” because of the help of friends and family, recalling “when there was snow on the ground and ice on the ground of course they would wheel me through that kind of thing.” Mark agreed with Karen’s comments, explaining that the “fairly mild weather” in his hometown allows him to “get out and around no matter what time of year it is.” He was certain that for athletes, “the weather and environment might not enable you to train as much or as hard as you could in other areas.” Beth notes that “if you go to the prairies ... you could be housebound the whole winter.”

Outdoor activities were definitely noted to be the most challenging when considering accessibility, however Adam related that he has discovered that local campsites have been developed to create a reasonable degree of accessibility, commenting, “the B.C. campsites are pretty much accessible”, and later adding “most of the B.C. campsites have washrooms, full accessible washrooms. So it makes a big difference. A huge difference.” He did note that perhaps not everyone would be able to reach the campground, stating that “I probably couldn’t have done that without a car.” Despite this one requirement, Adam was particularly pleased to note that the camping facilities were extremely accessible and even equipped to accommodate an individual with an even greater disability than his own.

Even for somebody, ... we had somebody who was in an electric power chair. They have electrical outlets at one of the washroom

*facilities so you could recharge the batteries for the power chair.
So, this person was a quad but still managed to be at the camp.*

Adam's experiences, and the comments of all of the participants in this study, outline how the environment of southern British Columbia is relatively accessible. Despite some occasional frustrations, the participants in this study reported that there were few physical barriers preventing them from accessing buildings, and opportunities for physical activity. Yet the explanation for their ease of access is likely related less to the lack of physical barriers and more to the society in which they live. A broader perspective of society can provide much needed insight into what really enables and disables individuals with SCI when attempting to incorporate physical activity and sport into their lives. It involves looking beyond the tangible concepts of physical access and exploring the complex social influences on individuals with SCI.

Access Means More than Curb Cuts: A Broader View

Equipment and Funding

Previously it was noted that even when a building provided physical accessibility, there was no assurance that once entering the building an individual would be able to participate in the physical activity of their choice. Adam recalled how even after he found a pool that was outwardly accessible, he was still required to jump into the water himself from his chair and he required assistance to get out of the pool. The front door of the facility was accessible, but the activity of swimming was not. A number of other participants related similar

stories, noting that although architectural accessibility was not an issue they faced challenges to accessing physical activity.

Karen described the difficulties she encountered when trying to operate the universal weight machines at a gymnasium, stating that "you can't use a universal gym unless it's set up, ... accessible." She further described the specific details of the difficulty, remarking, "you can't get access to actually changing, ... to reach in and change it because there is those stools that are permanent... ." Dave also reported experiencing difficulty with weight lifting equipment, observing that "there is a problem getting on and off some of the machines... ." He even reported having "fallen off a couple of times." John also noted that attending a gym in the community involved relinquishing some independence, commenting, "you're always getting someone to run over and help you." Karen reported that she eventually stopped going to a gym in the community because there was limited equipment that she was able to use independently and she felt that it was not worth the membership fee.

I used to go to gyms. You see, and I paid a full membership, you know, you are paying five or six hundred dollars for all this stuff. I couldn't use the tennis courts, I couldn't use the saunas for God's sakes. I couldn't use any of that. And I had to have a personal trainer to be with me to hold my legs on a bench press, to change the weights...

Karen revealed that she now attends a facility that has recently opened at the local rehabilitation center that, although small, provides accessible equipment. Beth reported discovering accessible equipment in her local

community center and Nicole reported that her local recreation center was “redoing their whole workout facility” to include some accessible equipment. John reported that he had begun to go to the facility in the rehabilitation center to lift weights, although he also continues to go to a community gym. He describes how he has developed a method by which he is able to use some of the weights independently, saying “ there’s a lot of free weights. And I carry them myself ... I can wheel with one hand and one weight and just carry it over, drop it down, and go get the other one.”

Without question, the men and women in this study found that specialized and adapted equipment was a necessity for them to fully participate in a number of recreational and sporting activities. Discussing one of his favorite activities, Adam described the special boats that enable him to sail, saying, “They have seventeen foot boats out there, seventeen foot Martins and they’re all designed to be adaptable, you know, from a chair.” He notes that having access to such specialized equipment has been “great, because [sailing] gives me a certain solitude and peace of mind.” Without such equipment, sailing would be impossible. Karen, who also enjoys sailing, noted that there are still some limitations as the adapted boats are small, stating “...there is only one seat. One seat and then there is a seat in the back if you need somebody, or if you want to take somebody. So with the three of us it’s kind of packed in there.” However, she reinforced the fact that she loved sailing and she now spends a great deal of time participating in the activity. She reported, “now I’m sailing and I volunteer there and get free sailing out of it, so it’s great.” She and another friend, also in a

wheelchair, became very much involved in the past summer, sailing "once a week together." It became a social gathering, Karen noted, "instead of going for coffee we'd go out on the boat together." This meaningful and important time for both Karen and Adam would be impossible if it were not for the specialized equipment that they use.

Participants reported a number of other activities in which a need for specialized equipment also played a role in their involvement. In fact, for an individual with a spinal cord injury, specialized equipment is required on a daily basis in order to provide mobility, a wheelchair. A number of participants remarked that over time their wheelchairs have changed into lighter, more technically sophisticated machines and that has provided them with more mobility. Mark commented,

I couldn't believe it when I got my first aluminum chair from my old steel chairs. It was ... it was just phenomenal. The difference it made in what I could do and how easy it was for me to get around with the lighter weight wheelchair. Yeah, it made a big difference.

As big a difference as the lighter weight everyday chair made over the older models, an equally if not larger jump in mobility for sporting events was remarked upon when discussing sport specific chairs. Karen, upon trying out a tennis wheelchair, revealed just how amazed she was at the difference and how it changed her perception of her abilities. She stated, "...I've never been interested in tennis, in that I didn't think that I could get there fast enough, but then I tried a tennis chair and went 'Wow!'." Adding later, "I wish I could have a tennis chair, and then I could do it." Other participants also discovered the

potential existed to participate in sporting activities with specialized equipment. Nicole had already tried water skiing, and both Nicole and Mark were investigating snow skiing again, utilizing a sit ski. Dave had investigated an adapted golf cart that would support an individual in an upright position to allow him/her to swing their club. Karen reported trying out a highly specified, newly developed chair called the Trail Rider. It functions in a similar way to a rickshaw and allows an individual with SCI to be carried along on a hike. All of these activities would be impossible to participate in using an everyday chair, as would almost any sporting activity. The importance of specialized equipment rather than an everyday chair was highlighted by Mark who noted that during rehab a number of people would play sports in the facility gym and "it was very good for the wheelchair repair people because we broke a lot of wheelchairs." Everyday wheelchairs can not handle the stresses of many sporting activities.

Quoted in the previous chapter, John related how his acquisition of another piece of specialized equipment, a hand cycle, was a turning point for him. A number of the other participants also related that a hand cycle was particularly important to them. Nicole reported "regularly" riding her hand cycle in the summer on pathways near her home and in a resort town in the mountains north of Vancouver, where bicycle trails are prevalent. She noted that by having the hand cycle she was able to participate in outdoor activities with her able bodied friends, recalling on particular day, "that was actually our most active day. It was an awesome day. We went ... we woke up in the morning and we went biking all around... ." The ability of the hand cycle to enable them to participate in

activities with able-bodied friends and family was also remarked on by both Mark and Karen. Karen, who had borrowed a hand cycle to try, came to love it. She remarked, "I want one." and "I wish it were mine." She discovered that she could ride with her young son, emphasizing the importance of that to her, she stated, "that made a huge difference. You know, because he wants to ... he needs more activities that way. Together." Grant also noted that his hand cycle was a way for he and his friend to ride together and "touch base" while they were "cruising around the block at nine thirty or ten at night while the kids are asleep." The ability of the hand cycle to enable individuals with SCI to spend more time with their family was also highlighted by Mark, who noted,

...as of the last few years hand cycling has become what we do as a family now that the kids are old enough and we've all got bikes. So really that's become kind of the family recreation day, is to go out for a hand cycle and the kids on their bikes and that. But then again, it is very much recreational, I don't race anybody, it's just something to do. Go out and wheel down to the park, and then the kids play in the park and then ride home.

Certainly equipment such as a hand cycle, removes some of the barriers faced by individuals and allows them freedoms that they once felt were impossible to regain. However, although all of the participants who had tried a hand cycle became enthralled by it, not all of them had their own and for many there were significant barriers to obtaining one. Although specialized equipment exists that can enable individuals to participate more fully in active pursuits, the same equipment can be a barrier to participation for those who do not have it.

Several participants noted that in order to have a hand cycle one must also have a great deal of space and a method of transporting it. Karen observed that “hand cycles are big. They are big and bulky...” She remarked that due to this, they are difficult to store for individuals with a small living space. She also noted that for an individual to transport it in “a little car” is impossible. Nicole also noted that transportation is an issue, stating that she usually needs to use a large sport utility vehicle, and assistance, to transport her hand cycle from her home to an area to ride it. She noted that her model of hand cycle can be broken down somewhat, and that by doing so it actually did fit in her friend’s car, however remarked that it was “smooshed” and not practical. Certainly it would be difficult, if not impossible to manage on her own.

Cost was reported by the participants in this study to be one of the biggest barriers to obtaining specialized equipment. When speaking of her wish for a hand cycle of her own, Karen noted that she would “love to invest in one”, but two things were preventing her, stating, “they take up a lot of space and the expense. Very pricey.” She estimated the cost at “about three to five thousand for a nice one”, but hoped that she would be able to purchase a cheaper model from a local company whom she had heard was making a cheaper model. Adam strongly believed that the cost of participation was a significant deterrent to his taking part in a number of physical activities, as evident in this exchange:

S: *What do you find are the sort of things that prevent you from being involved, or any obstacles that you’ve encountered?*

A: *Obviously, um ... finances or money sometimes. Definitely that is one of the biggest drawbacks, or one of the biggest barriers to a lot of activities.*

Beth also noted that cost is an issue. Upon hearing about hand cycles for the first time by the researcher she expressed interest, but immediately replied, "Oh, but I bet it costs a lot of money though." She noted that for herself cost is a big barrier as she is not working and adding, "well, I don't have any extra funding or whatever." Mark also noted that a lack of money "can be a big hindrance", noting that an individual's resources could influence their ability not only to participate in a sport, but to succeed. Discussing the advances in equipment, he reflected,

...the downside of it, a little bit, is that there is probably really good athletes out there that don't have the equipment and don't compete at a level that ... of their ability just because they might not be able to afford the equipment. And there's probably guys out there with really really good equipment that aren't as good as other guys, but can beat them because they can afford better equipment, so...

While finances were a considerable obstacle reported by participants in this study, several individuals also reported occurrences that allowed them to overcome this barrier, often through generosity. Karen, as noted above, was able to use a hand cycle loaned to her by a friend in exchange for providing a place to store it. She also recalled earlier in her life, when competitive sports were important to her, the sporting association funded her travel and expenses to get

to the competitions, remarking "that was funded. I never paid a dime." She also was able to acquire a racing wheelchair, although it was not easy.

My insurance company at the time, they did buy me a racing wheelchair, ... because we fought for it. My parents were saying; 'Mentally she needs this. She needs to be active.' and all that. They ended up paying for it, so I did have a good racing chair.

John also reported benefiting from a local charity, noting that "the orphans fund gave me a racing chair and away I went. I went into ... I've been in about six races." He also realized that when it came to financial resources he was considerably different from most individuals because his injury was due to a crime occurring while he was working. He received his funding through the criminal injuries fund of the local workers compensation board. He declared that due to this he receives "income assistance for all my wheelchairs and things", and was able to purchase his much loved hand cycle. He realizes that he is the exception, mentioning "there's a lot of guys walking around with nothing. And I see that."

Grant, while reflecting on the need for equipment in order to play some sports, related that in some instances purchasing the required equipment is unnecessary. He commented on the availability of 'sport chairs' for loan stating,

Nowadays ... you know, the access to wheelchair equipment is much more prevalent. So people can get them on loan, ... you can somehow get your hands on nine wheelchairs and you've got a basketball game, right? So you can compete with your friends and just put them in chairs and you're on an equal playing field.

Grant's comments were relating to able-bodied friends, however the same would hold true for any individual. Resources, such as one that would provide equipment on loan, could serve a vital link in enabling individuals to fulfill their physical activity goals. However the degree to which these resources are in place, and available to those who need them appears uncertain at best.

Available Resources: "I didn't know."

As discovered above, in order to have unconstrained access to participation in physical activities and sports individuals with SCI require more than just a front door through which they can pass. A number of other resources, such as equipment, funding, knowledge, instruction and organization are often required. Thus far, the role of funding and equipment in both enabling and disabling an individual's participation has been discussed. Attention will now turn to the other factors, with a focus on resources and sources of information in the community.

Several of the men and women in this study reported that after their injury, they were faced with a great deal of uncertainty as to their physical abilities and their opportunities for participation in physical activities. The uncertainty, understandably, appeared to be worst soon after the injury and as individuals gained experience and knowledge they became better equipped. Adam recalled the overwhelming situation he was faced with twenty-seven years previously when he was released from rehabilitation, recollecting "you're on a ... rehabilitation track and once you are out of that system there is really nothing ...

you're on your own." We expect that rehabilitation, and society, have evolved since then and more recently injured individuals should not be suffering the same distress. However, Beth, who was injured approximately six years ago, presented a remarkably similar situation. The following are excerpts from the researcher's conversation with Beth:

"I don't know. Can you do that again? I don't know."

"Well I don't ...I don't know...what can I do? I don't know..."

"I used to go biking a lot. But I can't do that now. What can you do? Besides just roll around."

"What activities are there...?"

"Hmmm ...[long pause] I wonder if there are any sports for me..."

"I'd like to try to get into doing something more but I don't know what."

Beth's comments are profoundly unsettling as they outline her inability to become involved in physical activity despite wanting to. When examining her situation, it is apparent that she feels she is on her own, just as Adam reported feeling almost three decades previously. She reported that in terms of physical activity and sport, she felt unaware of what was available for her.

Karen expressed frustration at her inability to find out information on programs and resources in the community, particularly for activities that already existed. She recalled an incident that had occurred a few years previous.

I wanted to get better and I wanted to feel better and safer in a boat and we ended up ... in my hunt, it took a long time to find ... um, to find somebody who could help with seating in a kayak. I looked all over the city, every kayaking place, everything. Until one day I got

the Paragraphic [newsletter for the British Columbia Paraplegic Association (BCPA)] and there was these disabled kayakers on the front of it and I was so angry because I had talked to the BCPA and nobody knew anything about this. The City of Vancouver pays for a program that is specialized water sports. They are all adapted water sports. And it took me until this happened, you know, after ages and ages of looking it took me this long for something to happen, you know it happened on my doorstep ... Yeah I stumbled across it and I was so angry at that, because the resource people I had called had nothing, and no information.

She notes that, although frustrated with the situation, the most troublesome aspect of it to her was that she was probably not the only one who could not find this resource, elaborating, "the way I see it, ... yeah, you know what, the program could have been cut ... and that's what is really frustrating to me. The resources to find out about all of this." She noted that at a later date she became concerned that the program was in jeopardy, stating, "I heard they were trying to move budgets ... and I wrote a letter and said 'No. No. No. You can not take this. This is too perfect.'"

In earlier years, after her initial injury and while living with her parents in a smaller community, Karen did acknowledge that the BCPA was responsible in part for her ever becoming involved in sports through speaking with her and her parents, adding "they use to come up and see how everything was." Yet, she stated that she felt that times had changed and the organization was losing its strength as a resource, particularly for those in remote towns, observing "the

BCPA is just overwhelmed right now. You know, they just can't be the resource they used to be because the population is too big."

Other participants also noted the need for resources and information for physical activities and sports. Dave remarked that he might consider trying the adapted golf cart that he had recently discovered, but noted "there is a technique, so you've got to get somebody who knows and can teach it to you that way." Nicole related an instance in which a lack of a qualified resource led to a disappointing sporting endeavor. A lover of water sports, she wanted to try water skiing utilizing a specialized sit ski. She had a difficult time and ended up returning the ski, feeling that the sport was unattainable for her. She later discovered that poor information was primarily to blame. Describing her failed attempts she recalled, "it was really disappointing ... and even my friends, able-bodied, they were like, 'I can't do this.' Like, you get up and it's so top heavy that you just topple over." It was only upon returning it to the dealer that she discovered she had an advanced model for expert skiers. She remembered the technician's comments, saying, "I guess probably they have one that is like outriggers with skis, so that once you get up you actually stay stable. Because this one, he said, you have to graduate to that." Nicole's inability to have correct advice and instruction left her in a terrible situation.

Not all of the men and women in this study had experienced such difficulty with resources. Some of the differences may be related to the time-period in which they were injured and other differences may result from different levels of persistence of the individuals themselves. Mark notes that although lacking

resources when he was in rehabilitation, he feels that the situation is much improved now, commenting,

...they didn't have the rec fairs, they didn't have the rec therapists, we didn't go out and try racing wheelchairs, or basketball, or kayaking, or camping. Those are all things that they do now that they didn't do back then.

He noted that the current practice of having 'rec days' during which rehabilitation clients can try sporting equipment is a concept that he really likes. Mark does not see the same difficulties that were eluded to by Karen, and in fact related that he felt "that if you are interested in playing sports, you can find what you want just by making a couple of phone calls." He related the important role of rehabilitation staff in assisting individuals in gaining awareness that could serve them for some time, noting that physical activity and sport may not be of interest initially.

They keep, ... they seem to keep really good track of that, you know, who's racing in what areas, who's playing basketball in what areas. So I think there's ... I think they do a pretty good job of it. Just the coming in here and doing the rehab fairs and, you know, everybody who is in here knows about BC Wheelchair Sports. And I think if you come here and you rehab here and you leave, then you automatically know about wheelchair sports and you know who to get in contact with if ..., you know because when you leave here you might not have an interest in sports. You might just be interested in getting home and getting your life back together again. But five years from now, you might be sitting around thinking 'Yeah, now it's time for me to get involved in sports.' You know, and your

memory will go back and think 'Oh yeah, that's who I get a hold of to find this stuff out.'

Dave also found the rehabilitation center to be a resource for him, stating that after a short while of living in the community and struggling with his strengthening program, he returned to the rehab center as an outpatient recognizing "I've got to get somebody to give me direction." Grant described how when he was newly injured, organized visits by individuals who were involved in the sporting community became a source of information and inspiration:

...they also had some key role model linkages where they would, you know, through the paraplegic association or wheelchair sport association try to get people exposed to possibilities in the areas that were compatible with them. In that case I was exposed to some people who were administrators in wheelchair sport, and some athletes who had come in to do some demonstrations and it ... , it had sort of opened my eyes a fair bit to the possibilities.

John also felt that having individuals already in chairs and involved with sport was "something that is going to rub off" and have a profound influence on newly injured individuals. Karen, despite her difficulties mentioned earlier, also reported gaining information through an organized day during which individuals could try sporting activities, much like the events described by Mark.

Despite the apparent role that the rehabilitation process can play as a provider of resources, several of the individuals in this study reported finding their information from other sources, or through their own persistence. Adam related that he was "on [his] own" after rehabilitation, yet he has found his own way to

the activities and clubs to which he wants to be involved, even starting his own disabled scuba diving club. He notes that he currently is involved with the local disabled sailing club as well as an athletics club through the provincial wheelchair sport association. Certainly for him any difficulties in locating information and resources has not stopped him from participating in activities. Yet other participants did not express this same ability to independently seek out activity and reported other methods through which they discovered opportunities. Beth recalled a time at which she discovered new possibilities for activity by accident, over her television:

...I didn't even know that you could play tennis if you were in a wheelchair. I just saw that on TV. They were looking for ... on TV, and they had a report or something on the news and they were looking for people. Um ... wheelchair people ... for wheelchair tennis. And I thought ... 'WOW! Tennis in a wheelchair?! No way!'

Although one of the most recently injured individuals in this study, she certainly did not appear to have gained the information in rehab that Mark had felt existed. She was uncertain of the possibilities that existed for her until she stumbled upon them, much like Karen described earlier. Nicole also described obtaining her information from a source somewhat outside of the rehabilitation center, noting that she "finds most of [her] information" at the local wheelchair dealer. She reported "you go there to get your chair fixed or whatever and they have all the brochures..." Nicole also finds that a wonderful source of information comes from the networking that occurs at a women's group that she has recently begun attending.

...the women's group that they've started was fun. Like I had no idea what to expect. I didn't have anyone to talk to when I was first injured, and it was good! And, I mean I've learned a lot too. Instead of just helping people that have just been injured.

Certainly, one of the best resources for individuals with SCI appears to be other individuals with SCI. A number of other participants reported discovering, or being introduced to physical activity and sport via a friend with a SCI, as opposed to an organized contact. Mark recalled that when he became involved in wheelchair basketball, a sport that he had no inclination towards participating in earlier, it was because of friends, stating, "it was really just one ... one guy that I had rehabed with that had gotten involved in basketball, and then he introduced me to a friend of his that was in a chair and then the three of us started playing." John recalled an important moment in his life, when he had reached a low point, when the intervention of a friend involved in wheelchair racing sparked an interest in sport and helped him turn his life around. He was recovering from sickness as a result of his downward spiral into drugs and beginning the process of becoming clean when a friend with whom he went through rehabilitation visited him.

He more or less said 'You can do whatever you want'. And he went through his ... as he went through his schooling for air traffic controlling I was getting higher on drugs, selling drugs, becoming a big drug dealer in the east end of Vancouver, and it was like ...[shakes head]... I was going down the wrong road. But after I got out after having osteomyelitis, Kelly was the first guy to see me. He was the first person I told. He said 'Hey, I'm there for you. If you

want to change your life and do things, that's fine'. He got me into racing. The next thing I knew, the orphans fund gave me a racing chair and away I went.

It is one thing to ascertain what resources are needed by individuals with SCI who want to become physically active, yet it is also important to consider how and, more importantly, when those resources should be presented. In his comments quoted earlier, Mark recognized that when in rehabilitation “you might not have an interest in sports. You might just be interested in getting home and getting your life back together again.” He notes that, as was true for him, the desire to become physically active may occur years later. Nicole’s comments corresponded with Mark as she noted that “they probably could have had more resources open to you [during rehab], but ... I can’t say how receptive I would have been.”

Several of the participants who did become physically active related that their involvement was a gradual process that developed over years, suggesting that the timing of the introduction of physical activities may be of importance. Grant recalled participating “as a coach and a trainer” for his able bodied friends sports teams soon after returning to his community. Nicole also returned to her school volleyball team to participate as a “team manager.” Grant noted that he then began “helping people in practices” and his exposure and reentry into sport began gradually. He notes that his volleyball/basketball coach was responsible for providing him with the opportunity to become engaged in physical activity

again, and from this he began to participate in larger sporting experiences building to his desire to rekindle his athletic spirit.

...the experience, combined with prompting, helped me see the scope of the possibilities, and I saw some amazing levels of athleticism and competition. And it started to fuel my sense of consideration of the sport as a vehicle that I wanted to pursue...

Karen also recalled her exposure to sport as a gradual process, as people introduced her to 'fun runs' in the community, which led to her participation in five kilometer then ten kilometer 'runs', and eventually to a significant involvement in physical activity.

I would fly down for the wheelathon, or do a seven K or a ten K, and do those wheeling. And then it got more serious in that I started getting invited to track meets, and then I became involved with field events, and practiced that and then in the winter time I had joined a volleyball team, I was playing volleyball. And competed that way. Wheelchair volleyball, wheelchair sports, wheelchair track and field. So it kind of started with just the fun run for wheelchair track, and doing that, and then it was like 'Oh! There's a meet in Langley!' or 'Oh! The BC Summer Games is here. Oh! There's different games here.' And so I'd just go. I'd just fly down and go.

Just as Grant did, Karen discovered sport through a gradual introduction to the possibilities and opportunities that were available. They report that resources were available, however their experiences, as well as the comments of the other participants, raises the question of when and how resources are best utilized.

The participants in this study expressed differing viewpoints regarding the availability and value of resources in the community to promote and provide information for physical activities and sport for individuals with SCI. Some participants felt that significant opportunities existed and were available to all individuals with relative ease, however conceded that that may be a more recent trend and may not have always been the case in previous years. Several other participants, however, remarked that they felt it was more a matter of serendipity, reporting instances of running across resources through happenstance and chance encounters with friends. Regardless of the degree to which these opposing viewpoints are legitimate, individuals with stories such as Beth's would indicate that some individuals with SCI are certainly left on their own. Her lack of knowledge of the opportunities for participation, despite her eagerness to find an activity highlights the fact that the availability of resources is definitely a factor in the activity levels of individuals with SCI.

Location

The term location is most often used in a geographical sense to position an individual in space. However, location can also represent an individual's place in time. Certainly, the comments made by the participants regarding their environment illuminate the role of their location, both in place and time, in influencing the ease with which physical activity and sport can become a part of their lives. It was noted above by a number of participants that their experiences

in rehabilitation and with accessibility were unquestionably related to the time period in which they were injured. Those injured more recently reported experiencing fewer physical access problems and many felt the availability of resources and programs providing opportunities for physical activity was improved in more recent years. These comments undeniably link their situations with time. A number of participants also reported that they felt their situations were also linked to their location geographically.

Several of the participants in this study had lived in smaller towns in British Columbia prior to moving to the Vancouver area, and Dave was currently residing in a smaller community on Vancouver Island, a short ferry ride from the mainland. All of the individuals who had experienced life in a smaller community recalled difficulties they experienced because of their locale. Nicole, when reflecting on her time in rehabilitation noted that individuals from smaller communities face some greater difficulties in attending a facility in the city.

...that's one thing that is a real downfall of the spinal cord injury unit is that, I think, with that type of injury you need your friends and family for support and when there is only one in all of BC, you're screwed. I mean your family can come maybe on weekends but it's not, you know, something that they can do all the time.

Adam noted that even prior to rehabilitation, in an acute care setting, one's locale could have a significant impact. He felt that after his injury, some medical problems he experienced were related to the size of the place that he was hospitalized, stating:

...it was a small country hospital so they didn't know what to do ... so they didn't want to move me so they basically left me in one place and they didn't turn me often enough, so I developed some serious pressure sores. And those really became so bad that they infected the bone and caused some osteomyelitis problems.

None of the other participants related such drastic problems stemming from their location, however when considering physical activity and sport a number of them described significant dilemmas. Karen recalled that she "did not know one person in a chair" in her hometown. Grant also recalled experiencing similar circumstances, stating, "...in a small town like ***** there were hardly any people with disabilities..." He noted that he felt this feeling of isolation could place greater strain on an individual and require a greater effort to become involved in activities.

*In ***** , yeah ... you know, I think if you're not a sort of a ... a self advocate or don't feel empowered to be able to negotiate your way through the obstacles of society, you become kind of a victim of what exists.*

Other participants, though speaking of different communities, echoed Grant's sentiments. Adam noted the lack of opportunities in smaller communities, stating, "a lot of small towns that are outside of Vancouver, outside of this main area ... I mean there are no facilities for a lot of these people." He further added that not only was there a lack of facilities, but a lack of resources and programs, stating "there are no associations involved." Dave, who currently lives in a smaller community noted that although he felt accessibility was not too bad in his

hometown, "it's not as accessible" as the larger city. He also felt that there were "more activities" available in a larger community. Karen stated that she felt "like [she] missed out on so much stuff" because of her locale. For Karen, her geographic location ultimately became a contributing factor in her decision to stop participating in wheelchair sport. As the only individual in her community involved in wheelchair sport, she notes that "when I trained I was basically on my own." She recalled feeling "separated" from the sports and stated "that's what I would say was kind of like the end of my career... ." She described how the solitary pursuit of athletics became uninteresting:

...actually that's what ended up ... the demise of my career I suppose. Um, when I was graduating and thinking ,you know ... it was boring to me then. I didn't like going up and down my street twenty times to make five miles for my training. It was the worst thing to get up, get in my chair my Dad would say, 'O.k. Go! Five miles!' and Boom, you're gone. I didn't have the support.

Grant, who experienced similar difficulties, related that when moving from his hometown to the larger city to enroll in university, his opportunities for physical pursuits widened tremendously.

...when it came time to graduate and move down here I was able to join a full time regular program in wheelchair sport and specifically I engaged in wheelchair basketball, table tennis, and a little bit of track and field.

None of these opportunities were available to Grant if he had remained in his hometown, and he reflected upon how significant an impact it could have had on his life if he had not moved.

...if I hadn't come to [University] and taken Phys Ed, I probably wouldn't have had the same sort of look at the sport as a sport. I would have probably ... you know, maybe ... maybe I might have looked at it as more of a disabled sport, I'm not sure. So, experience and circumstance dictate, sometimes, your perspective and I feel very fortunate about the experience that I've had.

Adam also related that his moving to the larger metropolis of Vancouver afforded him opportunities that he could not take advantage of in his hometown. However, at the same time he lamented the fact that individuals with SCI are placed in such a situation.

A: *I mean, there are a certain number of, ... a certain percentage of the population outside of urban areas and they shouldn't have to come to Vancouver, they shouldn't have to move to a different area to be able to access recreation.*

S: *Was that a factor for you in your decision to move to Vancouver?*

A: *Yeah! A big issue. For anybody, ... maybe they want to go back to their families. I don't have any family members here. All my family members are on the island, so ... and if I came back to the island, if I came back to a town of twenty thousand people, you know ... there's nothing there. There's no wheelchair sports association, there's no recreational programs, no disabled sailing, no ... there's nothing really. So a lot of people don't want to make that choice, you know. They go back to their family, ... or else they'd be alone.*

The men and women in this study positively identified the downfalls of living in a smaller community for individuals with SCI that want to become physically active. Yet, Grant also noted that he was able to overcome these difficult circumstances with assistance from his friends. He noted that his friends were vital in keeping him involved in activity prior to his move to the larger city, where his involvement grew. He noted that he was "sure [he] wouldn't have" developed the momentum of participating without the intervention of his friends soon after his injury.

*I had to continually redefine my world with the help of friends. And fortunately I have great friends, and fortunately I was able to make the best of a tough situation, because in ***** I was the only guy in a wheelchair. I couldn't organize a wheelchair volleyball game or basketball game. But I could organize some friends who wanted to come out and play ball with me and allow me to set and serve and play on a volleyball team, ... I mean ... stuff like that.*

He added that he felt that this approach was perhaps what was needed to assist individuals with SCI in small communities who were faced with a lonely existence in physical activity, noting that equipment could be loaned to able-bodied friends and family he elaborated:

In places like in rural or smaller communities where there aren't the numbers to be able to surround people with disabilities who have athletic interests with a bunch of family, friends, and other people who want to compete using the wheelchair as a vehicle, and see it as a positive thing. I think it's the only way we can be successful.

Increasing the exposure to disability in smaller communities is certainly a need voiced by Karen. She felt that, through no fault of their own, people in small towns are not aware of wheelchair sport because they don't get to see a lot of individuals with disability, stating, "they just don't realize what's going on outside." Yet at the same time she felt that exposure to wheelchair sport was well received by these same individuals, as was the case in her hometown. She noted, after participating in an event that had occurred in her home town, "for them to see that I was a part of that ... there was always write-ups in the paper then." Her comments reinforce the idea that, just as with the injured individuals themselves, it is exposure to the opportunities that sparks interest.

Dave felt that in a sense, the opposite situation was true, feeling that when compared to his small town, "the big city tends to notice you less, ... because it's a much more hectic pace." However, he also felt that there were more serious drawbacks for individuals with disabilities living in a bigger center.

...they are also more impatient. They don't ... they don't let you do things ahead of them. I noticed in the big shopping plazas, I used to go wheel up and down and ... um ... people pushing ahead to go on elevators and things like that. You know, it's incredible. Just incredible. The thoughtlessness of people.

The observations of the men and women in this study noted above stress the role of the environment surrounding an individual in enabling them to become involved in physical activity and sport after sustaining a life altering injury such as SCI. As this chapter has evolved, the participant's comments have addressed the physical environment, as well as the access to programs and opportunities.

During their conversations with the researcher, several participants also noted the impact of other individuals in both enabling them, and discouraging them. It is this aspect of the environment, the attitudes of others in society, which will now be addressed.

“Oh, they gave you a job, did they?”: The Attitudes of Others

Mostly it's a matter of getting people to challenge their own perceptions of what it's like to live in a society in terms of a disability. That often the biggest sort of hurdle that people have to get through ... it's other people.

This comment, made by Adam, reflects the profound impact that the prevailing societal attitudes and opinions can have on individuals with SCI. Several of the men and women in this study reported instances in which they noticed either a lack of understanding or negative attitudes regarding their disability. Nicole noted that people sometimes made “general assumptions” about an individual based solely on their disability, regardless of their own individualism. Dave also noted that he felt people would sometimes assume negative qualities about him with no basis in reality, stating “sometimes they treat you as though you're stupid rather than just [paralyzed].” He added that he felt these assumptions were based on an ignorance of what disability means, noting numerous times that “they just don't understand”, and adding, “and that bothers me. That really bothers me.” Dave points out, however that the lack of knowledge and understanding is universal, stating, “before this happened to me I would

have had no idea. ... You don't unless you go through it or you live with somebody closely... ." Grant recalled also noticing that although those close to him gained some understanding, the general public had limited insight into his capabilities, saying, "generically people would perhaps feel sorry for me or would perhaps limit their thoughts of my capabilities as a person or an athlete, and that always was a challenge."

Adam noted that in the past, he remembers two particular reactions by others to his disability, paternalism and avoidance. He recalled two examples from his past.

I remember a situation where you could go into a bar and you couldn't even buy yourself a drink. People would come over because they'd want to buy you drinks all night. They'd want to know your story. So there was a certain sort of paternalism that existed then.

...when I first came out in a chair, when I got out of the hospital and I was in a chair, you'd go to a park or something and kids would want to come over and talk to you and want to know why were you in the chair and mothers would come over and go "ooohh Don't bother the man in the chair.'

Adam recalled the frustrations he experienced, noting that he just wanted "to be accepted as a person who happens to have a disability." Yet he reported that "that's changed a lot, the general sort of acceptance", stating that " you don't see that as much any more." He reports that his experience now is that " people are much more accepting of the fact that people are in chairs and are quite

comfortable with someone with a disability.” Without question, society has changed drastically over the past few decades with regard to disability policy, however Nicole reported recent occurrences in which she was faced with negative attitudes towards her because of her disability that were quite unsettling. She reported recently being “kicked off” a tour group in Europe and being left behind because she was too much trouble to travel with, recalling that she was labeled as an “inconvenience.” She also recalled an encounter through her work that upset her, as it devalued her as a person based on negative assumptions.

*I mean this guy came up to me and he was about to ask me a question about ***** and ... he looks down and he says 'Oh! They gave you a job did they?' And I was just like, 'O.k., you know what? This is just not worth my energy. I'm just going to leave and go the other way and ... ' You know? I've had a couple comments like that ... it's frustrating.*

Despite stories such as this, and the similar accounts told by other participants, John remarked that he felt blessed to live in the society in which he does, stating, “In Canada, anything is possible. We get so much given to us, and we take so much for granted. And I see it all the time.” Without a doubt, another way in which the prevailing societal attitudes towards disability and their impact are clearly observed is through travel to other societies. Several of the participants in this study had traveled to other countries and observed the ways in which disability was treated. Mark noted poignantly just how the societal perspective of disability impacted individuals in that society.

When I travel I find it's really easy to get people to help me. Like when I was in Costa Rica and I needed to get up a set of stairs, all I had to do was say 'excuse me.' and I had like three people 'Oh, can we help. Let us help you up.' They seem to be much more into that there. I think here too a little bit is that over the years people here think more and more of people with disabilities need less and less help. So they don't offer it quite as easily as they offer it in third world countries, because third world countries ... they see the disabled people everyday who don't even have wheelchairs, pushing themselves around on the ground on a plywood with four caster wheels. So it's a much more visible thing. And they seem to be much more willing to help out.

Yet, he also adds:

The down side of that is that to people in those countries with disability it's a horrible stigma. To a lot of them ... um, the families almost ... it's treated like a curse on the family to have somebody with a disability, and then they're never let out of the house, they are never taken out in public.

These comments emphasize the social construction and definition of disability. It is interesting, also to note the contradictory views of disability in the foreign countries where Mark traveled. They treated him kindly, offering help and assistance, yet shunned individuals in their own society with the same impairments. Adam noted similar treatment of individuals with disabilities in the Middle East during his travels there, recalling "you never see anyone with a wheelchair there. If you are in a wheelchair or if you are handicapped you basically stay at home." In another country to which he traveled he noted a

similar reaction, adding that even an individual's own family reacted poorly to a disability.

...in their culture, there isn't an openness to anyone else in wheelchairs, or anyone with a disability for that matter. They are sort of shunned, put aside. And with family, it's kind of a thing ... well it's kind of a shame. The families are shamed when it is their son or daughter.

Like Mark, Adam found people in foreign countries treated him very differently, however and he remarked that they were "very friendly." Karen, although travelling to the more similar culture of New Zealand, found individuals "very welcoming" and "most helpful." Without question, the travels of these individuals highlight the strong impact that the attitudes of society can have on an individual with a disability. The society enabled Mark, yet at the same time disabled individuals of their own culture who had the same impairment.

Yet, as noted previously, one does not need to look to other societies to find examples of societal attitudes impacting individuals with SCI. When addressing their participation in physical activity and sport, the men and women in this study noted several ways in which the actions and attitudes of others affected their participation in activities. As outlined earlier, several of the participants noted instances in which they felt the general public underestimated their abilities, or even ascribed negative attributes to them based solely on their impairments. Several individuals reported that this lead to an increased level of self- consciousness and impacted their confidence in participating. Beth recalled

that although she has not become involved in many activities since her injury, she did attempt going to a local gymnasium.

I felt that I'd like to maybe try to build up the upper body doing, not aerobics, but weight lifting. So thought 'o.k., I'll try going to the community gym.' and so I did. But I really felt uncomfortable, because everybody was able bodied. I really felt uncomfortable. Didn't like it at all. I just, ... I felt like I shouldn't be here. ... So I just stopped going.

Dave recalled an incident also when, out of fear of the perception of the general public, it was tough for the recreation therapist in rehabilitation “ to get the people to participate because they didn't want to go out.” He noted the heightened sense of self awareness and vulnerability felt by the individuals with SCI, recalling “ they felt ... um ...embarrassed or incomplete or something, because they were going out in wheelchairs. And you'd go on a bus and everybody stops to watch you when you unload off the bus and then you load again.” He also related that he was reluctant himself at the time but decided to go, saying “Damned with the attitudes!” Yet more recently he noted that he was unsure if he wanted to continue to try and learn to golf using an adapted cart after, during a trial use at a local driving range “there were people, you know, ... gawking at us.” He added, “It just turns me off. It takes the enjoyment away from it.”

Several of the participants in this study clearly felt, particularly after experiencing negative interactions, a heightened sense of self consciousness that had a notable impact on their willingness to be involved in physical activities.

It was noted in an earlier chapter that a number of participants reported feeling more at ease when in a supportive environment such as rehab, where they felt others understood their circumstances, at least to some degree. Dave expressed the uneasiness he anticipated if he were to participate in a sport in front of the general public.

...you know, when you're in that hall and they are playing and they are surrounded by family and other people in wheelchairs it's great. But I couldn't imagine myself doing that away from it ... with normal people watching. With what I think is going through their minds. I was at a basketball game when I was at GF Strong, just before I left, and at halftime they put on a display of wheelchair basketball. Well, all the people where we were sitting, in the wheelchair section, knew what these people were going through. But the crowd, ... I just got the sense that there was pity. There was all that ... those horrible feelings that bug me. I may be imagining it, but I just sensed ... they look on people almost as if they were freaks. And that just really disturbs me.

It must be noted at this point that even the participants relating these stories acknowledge that the self consciousness could be largely their own barrier, however society most certainly plays a role in the situation as our own identity is constructed largely through social relationships.

Social Support: Family, Friends, and Society

Social relationships were reported by the participants in this study as being of prime importance in enabling them to participate in physical activity and

sport. Adam, noted that although he does have a close relationship with his entire family, his sisters are "very supportive" of him, as are his friends. He notes that because he associates often with other individuals involved in the same sports and activities as he is, he has a number of acquaintances who provide him with support. As well, Adam related that he was not as upset by the attitudes of others, noting that when he decides to do an activity, such as a recent goal of skydiving, he is "not going to let somebody else's attitudes stop [him]."

Other individuals also reported receiving support from those close to them. Beth noted that she finds most people in her life were more to "pushing [her] into activities. Not really [pushing], but more towards that as opposed to 'No you can't do that.'" Mark noted the importance of the support he received from his family.

My family support from both my wife's family and my family over the years has been phenomenal. There's nothing that I've said that I wanted to do that any of them have said 'No I don't think you should do that.'. They've always been behind me one-hundred percent. I think it makes a huge difference.

Grant related much of his involvement in sport to the encouragement and support of his friends when he returned to his hometown. He noted, " I don't think I was considered special or different in that environment." He noted that at the time he was injured, disability was viewed differently in society and integration was only beginning. He noted that he, too, was negotiating through similar issues as those around him.

I think again that general attitudes were pretty much consistent with my own attitude about my own situation. They were pretty

limited. Everyone was experimenting, you know, it was a big experiment. Everyone was on this journey together and we were all breaking ground, and so people were. you know, cautious, and sometimes...not quite sure how to take certain things. They all tried their best, and I didn't get a sense that there was any ill will or ... you know, there might have been some patronizing or what not but ... if there was I chose not to look at it. I chose only to see and surround myself with people who were positive and saw me as a person and brought value. So it was an experiment and they learned and I learned and we kind of stepped our way through it.

For John, the intervention of one individual in particular enabled him to begin a journey in sport that has helped him turn his life around. A friend, visiting him in the hospital told John that if he wanted to turn his life around he would help him get involved in wheelchair racing and channel his energy in a positive manner. John reports that his support provided him with the momentum to begin. He notes that the continued support and encouragement is of tremendous benefit, noting, "He'll phone me when I'm down, and in a down mode and he'll go 'Come on! Let's do something. Let's go for a race or something.'" Nicole also accounts a great deal of her ability to participate in activities to supportive friends who are not worried about the obstacles that they may encounter, saying, "I'd rather someone just think, you know, 'We'll deal with it when we get there.' Because it is something that you can overcome." Nicole reported having one friend in particular that is crucial in enabling her to participate in physical activities, reporting, "she is trying to get some more resources, because we want

to get into doing some more things ... like kayaking, skiing, anything that's available."

Unquestionably, the attitudes of these close social supports provide the individuals in this study with an enabling voice to counter the societal messages they often encounter. Surprisingly, a number of participants reported instances in which individuals that one would expect would be supportive and enabling, were actually not so. John noted his sadness in discovering that his best friend prior to his injury was unable to continue to support him. Where other participants found great support and strength in their best friends, John found none.

...well, my best friend won't even see me still. He hasn't seen me since before I was, ... well last time he saw me was before I was shot. He says he never wants to see me in a wheelchair. He says it would push him over the edge. I still try to this day to see him ... but I think, um...

Karen noted an instance in which a police officer in her home town greatly impeded her ability to train for wheelchair racing, severely impacting her enjoyment in the sport and contributing, at least in part, to her giving up the sport. She tells the story in this exchange.

K: ...I loved to wheel for long, long distances and train, ... and the police stopped me one day on the side of the highway and told me that I was harmful because people kept staring and that I was becoming a...

S: Distraction?

K: ...a distraction to drivers. And I was really upset about that. So I ended up having to go side roads here and side roads there, and

you know, and that ... I didn't feel as good about that because it wasn't as safe. I felt it wasn't as safe as being visible somewhere else, because I was on my own.

She stated that she eventually became bored on the repetitive circuit in her neighborhood and that, along with the solitary aspect of the training lead to the sport no longer being fun for her. For her a part of society that would normally be seen as helpful to its citizens, the police, ended up impairing her chances at finding enjoyment in sport. Nicole also found discouragement in an individual that she would least suspect to, her physical therapist. She noted that when she was in rehabilitation, her therapist would often underestimate her abilities and emphasize what she could not do, giving her an impression of being fragile. She felt that this dissipated her enthusiasm to become involved in sport. In recalling a particular instance in which she found, against her therapist's ideas, that she was able to swim without floats.

...I think too they treat you really fragilely a lot. Um, that's probably not even a word but, ... You're not really that fragile. And I don't think you really realize that yourself until you get out and do things on your own. Like just for example with the swimming. Um, I mean basically because your legs are atrophied they float anyway. I mean, you go in water it's great, they float. But I think they ... I mean I understand the other side of the coin too, where they don't want you to be hurt and ... but there's also limitations if you are given the attitude that you can do it, it's a lot easier to do. Whereas if you're told that 'This is going to be difficult and da, da, da,... .' Then ... [you're] more apprehensive..."

Without question, the individuals in this study noted that they were influenced significantly by the attitudes of others in society, both close relatives and friends and members of society at large. In the previous chapter, the struggle with rebuilding a damaged identity was discussed. As our identity is largely socially constructed through our perspectives of the views of others towards ourselves, having accepting, encouraging, and supportive friends and family appears to be important. This raises concern for those who are not surrounded by family and friends and must rely upon social support in the broader context. The stories noted previously in this chapter have described the potential for individuals to miss out on available resources in their area and has highlighted the holes in the support net that is designed to help individuals with disabilities. Without social supports from friends and family, or society at large, involvement in physical activity and sport becomes difficult. Karen, who earlier in this chapter had noted a lack of support in training by her friends, is a prime example of this. Reporting a lack of support from local officials, and the previously mentioned lack of support by friends, she felt that the combination of the two led eventually to her retiring from wheelchair sport.

Although recognizing that in the process of adjustment to their SCI a significant portion of the burden to challenge attitudes falls upon their own shoulders, the men and women in this study undoubtedly felt the influences of societal attitudes and social support. They recalled instances in which the attitudes and support of those around them provided an enabling force, as well as instances in which others served to be a discouraging force. Certainly, the

individuals by which one is surrounded determine to a significant degree one's ability to become physically active.

Changing the Perspectives of Others

Several participants remarked that they felt that their participation in physical activity and sport was able to assist in changing, at least in some degree, the attitudes of those around them. John noted that after building up his strength again through weightlifting and hand cycling, he once again noticed instances of admiration from others of his physique. He recalled that when riding his hand cycle, many people passing by would remark, "Wow. You look really neat in that thing. Where did you get that?" As someone who prior to his injury was seriously involved in weight lifting and proud of his muscular build, he was thrilled when once again others remarked on his strong body, stating, "...it's a good thing because I come out and people will look and say 'Man, you're built.' And I can just say I put some time into it and it just makes me feel good." The recognition is also most certainly beneficial for John's own attitudes towards his disability, boosting his self esteem and providing him with the regained identity of a strong individual, however the impact of his physicality on others is notable.

Grant recalled an incident in which his abilities, demonstrated through sport, drastically changed the views of an able bodied competitor at an integrated competition.

...when I went to an integrated competition in the Northern Games, the guy I was playing against, at first when he saw me in a wheelchair he was taking it easy until when I beat him in the first

game and then he really tried hard. Well, he beat me three games to two, but the point is that he had to try hard and treat me as an equal, otherwise he was going to get thumped. So I gave him a reality check. So it was good.

Karen, who had noted that she was generally on her own when she was training for wheelchair sport due to both the lack of others with disabilities and the lack of support by friends, recalled how the perspectives of those around her changed once they observed her in competition.

*...when the games came to *****...and, you know, I ended up winning something like four gold medals and everything else. I was torch bearer for the games, and..., you know, most of the people ... most of my friends, most of my family had seen a side of me that they had never seen, and seen that community that I belonged to that they had never recognized before. I was just 'Karen' in a wheelchair, right? It wasn't about a disability or anything like that. I was always integrated and, um, so when they kind of saw me with this group of people in chairs it was like I had this whole other side to my life.*

She reported how profoundly the experience changed the attitudes those around her, adding,

And then after that, though, ... training. I had people. I had my boyfriend, I had my friends coming out to time me at the track, and to help me. I got a bit more support then. They realized that it was serious and that there was a bit more involved in it.

This story powerfully demonstrates that physical activity and sport can not only change the perspectives of those who participate, as was discussed in Chapter Four, but also the perspectives of those watching from the sidelines. The image of her competing in an athletically demanding environment ran counter to the views held by Karen's friends of what it meant to have a disability, providing them with a new perspective through which to view Karen. If indeed, as participants in this study have related, the disabling attitudes of society serve as a barrier to participation then it would seem that physical activity and sport for individuals with SCI could serve as a transforming power for societal attitudes. This topic will be discussed further in the next chapter.

Looking in a Mirror? –Reflecting Societal Attitudes

It is important to note, when discussing the impact of societal attitudes, that the men and women participating in this study are also a part of the society in which they live. As such, they too have developed their own opinions and perspectives on disability prior to their injury, and these conceptions likely persist post-injury. A number of authors have noted that a disabled identity is socially constructed from the values and beliefs of mainstream society.^{107, 110} The participants in this study, as members of that society, also presented with a broad range of perspectives regarding disability. These perspectives, just as the perspectives of the society around them, functioned in both an enabling and disabling manner.

Dave, who noted that he struggled with acceptance of his impairment, demonstrated a negative attitude towards all activities that were adapted, noting that " I don't want to do anything ... too much with things adapted. I want to do things the real way. The way they were supposed to be done." Beth described similar perspectives on adapted activity, noting that to her, aerobic exercise in a wheelchair with the upper extremities was "not really aerobics." After relating that she really missed cycling, and being introduced to the concept of a hand cycle she replied, "well then I may as well just be in a wheelchair. It's the same thing. That's the way I look at it. I kind of look at it as I'm still just pushing..."

Karen demonstrated an opposite viewpoint of acceptance of adapted sport. She recalled enjoying immensely a hiking trip in which she had to totally surrender her mobility by giving up her wheelchair and being carried on a specially designed 'Trailrider' by companions. She noted that "you are surrendering, but I didn't feel that disabled. I didn't at all.", adding that the benefits of the experience to her far outweighed any discomfort and in fact presented her with opportunities that she otherwise could never experience, always missing out on hiking trips by her husband and son.

I was privy to everything. Everything that [her son] said and did and, you know, got to see some great moments of them walking together and [her son] walking with me and picking a daisy for me and ... that wouldn't have happened anywhere else. That was very very special. To me that's, you know, it's a great sport.

She also noted, that she was able to fulfill a dream by sitting alone in a field of daisies, and pointed the researcher to a photo of the event displayed proudly in her home.

Mark, who also had heard of the 'Trailrider' noted that not all individuals would be as accepting to such a large degree of adaptation to an activity.

...the problem that I see is that most wheelchair users want to do it themselves. The idea ... you're going to have a hard time convincing people that being put on a carrier and being carried into the wilderness by three or four other people as making it accessible. A lot of people are going to say ' No that's not making it accessible to me. Accessible to me means that I can get there on my own.'

Mark does concede that as there will likely be a wide variety of acceptance, there will also need to be different approaches to physical activity, stating "Now, that's all ... it's not going to be possible for everybody and there will always be ... there will be a need for both avenues to get people into inaccessible areas."

Both Dave and Beth, who were the most hesitant to accept adapted activities and related having the most difficulty accepting their injuries, were relatively newly injured when compared to the other individuals in this study. Certainly, the issues of acceptance and creating a new identity, as discussed in Chapter Four, play a role in creating their outlook. Yet, our identities and attitudes often reflect those of our environment and therefore the discrepancy between their perspectives and that of Karen may be accounted for as part of the normal

range of societal views. Certainly the interactions between society and the self in light of physical activity and sport are numerous and complex and individual variations abound. Grant, addressing this complexity, eloquently reflected:

I think what we really have to do is spend more time understanding human nature and people, and try to surround people ... and not try to fix people and change their motivation ... , and just surround them with liberating opportunities to fill the objective of being physically fit ... and that could be outdoor hiking, it could be kayaking, it could be swimming, it could be ... you know, it could mean accessibility to an integrated fitness club with your friends, active yoga, it could be pilates, it could be sport in certain ranges and areas. And whether it's able bodied or disabled I think that's inconsequential if we understand what the objective is and provide the best vehicle, ... and I think that's what life's about. And if we take that approach towards physical fitness then maybe we'll take that approach towards other areas of life and ultimately be true to people who happen to have a disability and treat them as people first.

Grant's comments raise the issue of discovering the best approach to take in order to enable individuals with a SCI to take advantage of opportunities for physical activity. In the next chapter, such issues will be addressed, through an exploration of the relevance of these participants' words to those with SCI, rehabilitation professionals, and society as a whole.

CHAPTER SIX

CONCLUSIONS AND DISCUSSION

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Introduction

This study originated from both personal and professional observations that individuals with SCI often experienced difficulty in attempting to incorporate physical activity and sport into their lives post-injury while at the same time recognizing that inactivity was potentially detrimental. An examination of the SCI literature confirmed the lower activity levels of individuals with SCI, with a number of authors noting that those with SCI often participated in very little physical activity.^{2, 3} Furthermore, several authors noted that the high levels of inactivity could lead to a number of medical complications and that an increase in physical activity resulted in improvements in both physical^{6, 15, 25, 35, 36, 39, 40} and psychological⁴⁸⁻⁵⁰ functioning. However, what seemed to be inadequately investigated in the literature to date was an examination of the factors that enabled individuals with SCI to become physically active. A relatively small amount of literature could be found that has examined the more concrete barriers to exercise, such as transportation and accessibility to facilities.^{53, 59} There is a paucity of information of the range of enablers and barriers of all types derived from the perspective of those who are undergoing the experience first hand. In exploring disability research, it became evident that society is thought to play a large role in the construction of disability and the creation of barriers faced by individuals with SCI.^{12, 62, 66} It was with a recognition of this large influence of society that this study was designed to explore the issues faced by individuals

with SCI in incorporating physical activity into their lives through the viewpoint of the social model of disability. In order to avoid placing the spotlight solely on society, and thus create an unbalanced evaluation of the issues, a recognition of the individual's role was incorporated into the study's approach.

It is with this background that the fundamental question of this study was proposed: What enables or discourages individuals with SCI from becoming involved in physical activity and sport? The individuals in this study not only expressed the potential benefits of activity, but elucidated a number of issues that both enable and dissuade their participation.

This chapter will reflect upon the broader issues arising from the words of the men and women in this study. The relevance of their experiences to rehabilitation professionals, planners of disability sport, as well as friends and families of those with SCI and spinal cord injured individuals themselves will be explored. As well, the limitations of this study will be outlined and the applications of this work for future research will be discussed.

Reflection and Discussion of Theory

The comments and experiences of the men and women in this study appear to confirm the appropriateness of the social model in exploring the issues faced by individuals with SCI and their participation in physical activities and sport. Several of the participants noted a number of factors well beyond their control that had a profound influence, both in positive and negative ways, on their ability to lead an active lifestyle. From inaccessible facilities, to a lack of available

programs, and negative attitudes towards them, participants illustrated the profound capability of society to influence their lives. It must also be noted, however, that the individuals in this study also recognized that there was a significant impact created by their own attitudes and actions, often stemming from the difficult process of re-embodiment after their injury. The degree to which participants ascribed responsibility to these internal factors was largely unexpected.

The results of the present study are consistent with those of Kinne and colleagues¹¹¹ who reported a similar discovery in a recent quantitative study of correlates of exercise maintenance for individuals with mobility impairments. Citing that although theoretical literature about disability led to an expectation that external barriers (lack of access, transportation, funds, and social support) would be the most important, they found that attitudinal factors of the individual themselves (self-efficacy and motivation) were the only significant predictors of exercise maintenance. However it is important to consider that the two elements are likely substantially interrelated and difficult to discern from individual accounts. In their study, Kinne and colleagues noted,

...the lack of specificity may lead some people to class their issue as 'being too tired' or 'not being interested', where another would call the same issue 'lack of money', recognizing that with more money, less energy would be spent to participate, and that energy would make it possible to be interested.^{pg.21}

This quote highlights the difficulty in attempting to distinguish between 'internal' and 'external' barriers. It is particularly relevant to the issue of self-

esteem and self-identity after a SCI, which was reported by several of the individuals in this study as impacting their participation in society and an active lifestyle. Is self-identity considered an 'internal' issue or is it a broader, societal issue? Our self-identity is certainly constructed by the way in which we are viewed by others, and in that sense it could be considered an 'external' issue. Yet at the same time, inherent in the word self-identity is the root 'self'. Without question, matters of distinction become unclear.

In fact, it must be pointed out that although written in a linear, segmented fashion, the issues discussed in this study are by no means isolated from each other. On the contrary, the numerous factors affecting their participation as reported by the individuals in this study are interacting and overlapping with each other. For example, an individual's geographic location impacts upon not only the physical accessibility of local facilities, but also the availability of programs and equipment. From another viewpoint, the availability of accessible facilities, programs and equipment stems from the attitudes of those in that society. For the purpose of clarity and ascribing a format to the discussion, attitudes were separated from physical barriers, and resources were discussed separately from the physical environment. Yet, in reality all of these concepts interact and intersect to create the larger picture. It is hoped that through exploring all of these concepts, the larger picture becomes clearer.

Physical Benefits ... but so much more

As was outlined in Chapter Two, individuals with SCI face an increased susceptibility to health problems after their injury. Cardiovascular and respiratory disease, as well as urinary tract infections are noted to be among the primary concerns for morbidity and mortality post SCI.^{15-18, 23, 37} Outwardly trivial, but equally dire, consequences such as pressure sores are also common.^{24, 25} Noting that a large number of individuals with SCI are inactive after their injury and that inactivity is likely a contributing factor to these complications, physical activity and sport have been investigated as a method to combat the physical problems occurring post SCI. In a number of studies, investigators have found that those individuals involved in physical activity have fared better than their inactive counterparts.^{6, 15, 36}

Bearing in mind that there was no attempt to investigate their physical health with any statistical significance, the experiences of the men and women in this study seem to be consistent with the previously mentioned studies. Beth, as an individual who was admittedly very inactive since her injury, noted that she was aware of a decrease in her cardiovascular abilities. She noted that with any strenuous activity, she was "huffing and puffing", and expressed frustration at her loss of fitness noting that she "wasn't like that before." Several other participants described physical activity as being beneficial to their overall health. John related how he had rebuilt his physique to become just as strong as he was before his injury. Dave noted that with his activities, he too was definitely "getting stronger." Adam remarked that he felt that when physically active he experienced much

fewer medical complications, such as bladder infections. Although unable to suggest or establish any causation between physical activity and health, and not designed to do so, this study notes that the participants who were involved in physical activity and sport reported experiencing physical benefits.

In what is perhaps the more relevant observation of this study, the participants remarked on how physical activity and sport provided them with benefits far beyond those of physical well being. Adam described the experience of outdoor activities as a way of "getting away" and felt that it was an "almost spiritual" way of being at one with nature. In a study exploring the meaning of sea kayaking for individuals with SCI, Siegel-Taylor and colleagues⁶⁹ observed similar responses, with participants stating that kayaking provided them with "an overall feeling of high", and that going on the water was a whole other exciting world. Participants in the sea kayaking study also noted that they enjoyed the social interaction the activity provided. In the current study, Karen, Mark, and Grant noted that the recreational activities they took part in were a method of spending time with their family and friends. Mark stressed the social benefits of activity, noting

I like the social aspect of it too. I think over and above the need to go out and exercise the social aspect of wheelchair sports, I think, is really, really important. I think it's as important as the physical aspect of wheelchair sports.

Certainly a lack of social interaction can be damaging to one's enthusiasm for physical activity, and was cited by Karen as a primary factor in her decision to

leave wheelchair sport. The significant impact of social supports and of society in general will be discussed later. What is notable, and will be discussed here, is the strong personal role that physical activity and sport have the potential to play. For several participants, physical activity and sport appear to be a critical part of the process of redefinition of self and re-embodiment that occurs after a SCI.

Several participants remarked on the struggle to adjust that they had experienced after their injury, and the difficulties in redefining what disability meant to them. Many individuals reported having a significant struggle with acceptance and some are continuing to struggle to the present time. Dave and Beth, as the most recently injured individuals, demonstrated that perhaps time is a factor in the process of developing a new identity and accepting the injury. Dave is still very focused on his prior lifestyle and identity and is determined to return to his previous activities, utilizing physical activity as a way to strengthen his body in an attempt to do so. His incomplete injury, with some functional return to date, allows him to do this, and he is therefore perhaps not fully able to begin the process of re-embodiment for a body that is still undergoing some change. Beth appears to be just beginning to attempt to become involved in activity again after five years of struggle. She recognizes that she has changed, experiencing a physical and emotional decline, and she reports wanting to begin doing activities that she once did. This period of inactivity, when compared to the other individuals in the study, does not appear to be unique to Beth. A number of other individuals, such as Mark also described a period of time during which physical activity was not of importance to them. It appears that there is a period of time,

which is short for some and long for others, during which there is a struggle for acceptance of the disability. Almost every participant noted that there was a time during which physical activity was absent, while they struggled to define what having a disability meant to them. Some stated that it was after this period of time, that they were ready to begin physical activities and sport once again. For these individuals, this period of inactivity was used to focus on other activities such as school, work, and travel. These activities likely helped them to redefine their lives in a meaningful way. For a number of others, physical activity and sport became part of the process of redefining self and ascribing meaning to their lives. John powerfully related how his discovery of a hand cycle led him to discover that "there is life in a wheelchair", and come to the realization that "you can do whatever you want in a wheelchair. You just can't stand up." Grant also described that physical activity was used as a metaphor to pursue rehabilitation and re-establish his life. Through sport, he discovered that he could once again have the identity of an athlete.

The need to establish a new identity after a SCI has been reported by others. Carpenter¹⁴ in her exploration of the experience of SCI, noted that redefining self, redefining disability, and establishing a new identity was a common experience. The participants in the present study have described a similar process, and the ability of physical activity and sport to assist in this process has been reported. Other authors have noted that physical activity and sport could perhaps play a role in these larger issues. Siegel-Taylor and colleagues⁶⁹ described sea kayaking as assisting in the construction of a positive

new identity, noting that through the new achievement of kayaking participants were able to redefine themselves with regard to their own perceptions of their abilities as well as societal perceptions. They noted that the activity provided the individuals with a discovery of "I can do this!", challenging their perspectives of their own abilities and enabling a construction of a more positive identity. Trieschmann¹¹² concurs, stating that recreation and athletics provide a rewarding set of "I am's" to offset the negative societal messages. The effect of participation in physical activity and sport on self-image has been discussed by a few authors. Taub and colleagues¹¹³, in a recent study of male college students with disabilities found that participation in physical activity and sport had profound potential to lead to improved self-image. Other studies have echoed these findings^{51, 73}, stating that physical activity significantly improves an individual's perceptions of their abilities and is particularly of relevance for individuals with a negative self-concept.¹¹⁴

It appears that whether it is physical activity and sport, work, school, or another activity, having a positive forum in which to develop a positive identity is crucial. Those individuals who did not return to being a 'student', 'employee', 'traveler', or 'athlete' soon after their injury floundered and had more difficulty. John, although later becoming involved in sport, is an example of an individual that did not immediately present himself with an opportunity to develop a positive identity after his injury. He struggled with acceptance and that struggle, as well as being unprepared for handling the financial settlement he received after his injury, led him down the wrong roads to a life as a drug user and dealer. Beth

and Dave also did not have an identity as a 'student' or 'employee' to return to after their injury. They both related that they struggled, and continue to struggle, with their new identity as an individual with a SCI. Dave is focusing all of his energies on regaining his identity as a 'golfer' and an individual that can walk. Beth appears unsure of herself and what she can do. For these individuals, the lack of a positive label of 'athlete', such as Grant, or 'world-traveler', such as Adam, perhaps leads to their apparent struggle. For Grant and Karen as athletes, Nicole as a student, Mark as an employee, and Adam as a world-traveler, identities were created that presented them as 'able' rather than disabled. This likely has an effect on their perceptions of themselves, as well as the perceptions of others around them. While not conclusive, it is interesting to note the potential that physical activity and sport has in assisting an individual to create a positive identity after the disruption of a SCI, supported by the experiences of the participants.

All active participants noted that, whether used as a method to redefine self or stemming from an already re-embodied self, physical activity held a profound meaning for them. It was described as being important for the physical, social, spiritual, and emotional aspects of their life. Re-establishment of one's identity is a critical process that must occur after such a life-altering injury. For the individuals in this study, a way of reconnecting with their previous self and providing a positive meaning to their lives was crucial. Involvement in physical activity and sport was one of the primary ways by which individuals described doing this.

The Perspective of the Social Model

The individuals in this study remarked upon a number of factors outside of their control that had a profoundly discouraging impact on their ability to be active. It is important to recognize these societal barriers, as well as the enabling factors, in order to gain a full appreciation of the circumstances faced by individuals with SCI. The social model of disability appears to be an excellent model through which to explore these issues. Crow¹² contends that the social model aims to take the focus away from the individual's impairments and highlight the environmental, attitudinal and social barriers that serve to disable an individual. The men and women of this study without question noted the social barriers that they faced.

Although recognizing that it is improving with time, a number of individuals remarked on inaccessibility of facilities in their community. This was particularly true for those in small or rural communities. Participants also remarked that even when they could gain entrance to a facility, often the lack of equipment suited to their needs provided yet another barrier. A fitness facility with an accessible exterior but no usable equipment is rendered an inaccessible facility, as is a pool with an accessible front door but no lift or ramp to get into the pool. The men and women in this study remarked on several similar occasions in which they were not able to access fitness facilities that were supposed to be accessible but fell short. Several participants noted that these obstacles were gradually being removed and some of their local facilities were beginning to provide accessible

equipment. Nicole stated that her local community center was installing new, accessible equipment. Karen and John both reported attending an accessible fitness center that had just begun at the local rehabilitation facility. However, again particularly in smaller towns, the basic access to facilities remained an issue.

For a number of wheelchair sports, specialized equipment is required. Several participants remarked that a lack of access to this equipment, not in a facility but to obtain for personal use, hampered their ability to be active. Hand cycles, for example, were found by several participants as a tremendous method to develop a sense of freedom and at the same time participate in physical activity. However, a number of individuals in this study remarked that hand cycles were out of reach for them, due to expense and their bulky nature that makes transport and storage difficult. Chairs designed for playing tennis or basketball, or even enabling an individual to go to the beach without sinking in the sand are all specialized, rare and expensive.

The availability and affordability of this equipment depends, in part, to the policies and structure of society. Mark, whose job deals with supplying equipment for those with SCI, remarked during his interview that a number of companies trying to make specialized equipment to allow individuals with SCI to be active were struggling and many have gone bankrupt despite having developed useful equipment. When discussing chairs designed to give people access to the outdoors he remarked,

...you look at what's available in all terrain wheelchairs, there's very little out there. Very, very little ... a couple of the ones that have

been on the market we lost. The companies have folded so they're not around.

In a society in which SCI individuals are by far a minority, the ability of a business to develop and market products to such a small portion of the population is questionable at best. This, in turn, hampers the ability for individuals with SCI to gain access to products that have tremendous potential for increasing their opportunities. With a small potential consumer base to which to sell products, equipment manufacturers must sell their products at a high price, and the potential for development and innovation remains low as long as the demand for such products remains low. In this way, the economic structure of society hampers the ability for individuals with SCI and other disabilities, to obtain sophisticated and specialized equipment that could enable them access to greater opportunities in physical activity and sport. As noted by the participants in this study, even for the equipment available today, price and access remain a priority. If demand for equipment were to rise, perhaps even through increased awareness of the possibilities, then providers could develop and produce more equipment and costs would fall. An increased demand could eventually lead to an increased availability in programs providing such equipment. Several individuals noted that they were fortunate to have programs available in their region that provide or loan equipment, however an individual's location became a factor with these loan programs primarily existing in larger centers.

Without question, the men and women of this study remarked on the influence of programs and resources in their community, such as the equipment

loan programs. Some individuals noted that available programs and opportunities assisted them in becoming active. For Karen, visits by the local SCI association to her parents and herself were an impetus to her athletic career. Grant also noted that the local SCI association, through visits by key role models during his rehab stay, was integral in providing him with information on what was available in the world of sporting activity. For many, however, resources for physical activities and sports were limited and ineffective and they remarked that they were on their own. Karen, although having a positive experience early on, noted that in more recent years she has found it very difficult to find information from an appropriate resource regarding her participation in activities. When trying to find information regarding kayaking, it was only through serendipity that she came across a resource, after calling all appropriate resources in her area. Of note, however, is that the program she was looking for all along was already in existence in her area. Her story and the other anecdotes noted in the previous chapter dramatically outline the problems faced by individuals with SCI in trying to find opportunities in physical activity and sport. In fact, many of the participants reported that it was not an official organization or resource that assisted them in becoming active, but their friends and family.

Remarking that their friends and family were by and large supportive and encouraging of their endeavors, participant's comments further revealed the relevance of the social model to their situation by observing the influence of the attitudes of others on themselves. Those individuals who traveled remarked on the profound differences observed in societal perspectives of disability. Mark,

who was gladly assisted and supported in a foreign country, observed that individuals with disabilities from that country were treated very differently. A number of authors have described the racial, ethnic, and cultural factors that influence disability^{115, 116} and certainly this influence was noted by the individuals in this study. Most remarkable, however, are the observations by the individuals in this study not of the attitudes in other countries, but in their own society. A number of participants related experiencing negative attitudes to disability and often felt a stigma associated with their disability. Nicole noted an occasion in which an assumption was made that she received her job solely because of her disability and not through her skills. These stereotypical viewpoints also were noted to discourage involvement in physical activity. Dave described instances during which people "gawked" at him, noting that he felt "like a performing seal", or a "freak." Mark and Grant both described "patronizing" attitudes that existed when they were first injured. Even with close friends and family, some individuals noted that stereotypical views of disability influenced the support they received after injury. John related that his best friend prior to the injury "won't see me still", afraid of how he would react to seeing John in a wheelchair. Karen remarked on the lack of support for training she received from friends and family until they saw her in competition and realized that her athletic endeavors were worthy of support.

Unquestionably, the stories of the men and women in this study confirm that the stereotypical view of individuals with disabilities as unable to be truly athletic exists today. Grant observed that an able-bodied competitor initially

scaled down his effort, underestimating Grant's abilities. Karen remarked that her lack of support in wheelchair sport at least partially came from a lack of knowledge by others as to just how competitive and athletic her endeavors were. A number of the participants described experiencing patronizing attitudes and instances in which they were viewed as disabled, in the literal sense. It is not surprising that their athletic endeavors would be looked on differently than those of individuals involved in able-bodied sport. A recent study by Schell and Duncan⁷⁸ investigated this phenomenon in the world's premier sporting events, the Olympics and Paralympics. In their analysis, they found that many of society's stereotypical ideas of disability were perpetuated. As a whole the coverage, when compared to Olympic coverage, was sub-par in terms of production value. As well, commentators were found to trivialize Paralympians' losses, rarely described athletic performances in aesthetic terms, and underplayed the importance of team conflict, winning, and competition. There was little commentary on rules, strategies, and other aspects of the sport and much of the broadcasts focused on the 'human interest stories' behind the athletes. The message that this style of broadcast may send is that the Paralympics are not to be considered equal to other major sporting events. The lack of focus on rules, times and results were felt to symbolically deny that what the audience was watching was a true sport.⁷⁸ The focus was placed on the disabilities and not on the sports themselves. One Paralympic competitor expressed her frustration with this perspective:

Until people get over the 'Oh, how inspirational ... give the freaks a hand, they made it' attitude ... if they do get over it and say, 'Yes,

they are elite athletes, yes they train as hard, they do deserve to be there, and we are going to watch and cheer them on' ... until they get over the freak show mentality, it (Paralympics gaining respect) just won't work.^{pg.27}

There is obviously a potential for frustration among individuals with disabilities that disabled sport receives such a demeaning and patronizing view by society. Adam noted that he felt that athletes with disabilities were treated as lesser than able-bodied athletes and he was upset that the Paralympics were treated as an "addendum" to the Olympics. Grant, however remarked that he felt that an expectation to be treated equally was unrealistic, remarking that not all sports, whether able-bodied or for individuals with disabilities have the same degree of recognition. He noted, "some sports might be really exciting and entertaining and others are boring as hell and will only have an elite group of people who are interested in it and that's life." He did recognize that the Paralympic games provided amazing examples of athletics and competitive sport, however questioned the ability to break free from the disability stigma through an event that is structured and designed to highlight disability. In describing this dilemma he remarked,

...I just don't believe that through the Paralympic Games we'll ever really truly send a message of the eliteness of the athletes and....convey the respect that's due to those athletes. They're incredible athletes ... I know that they are every bit an athlete as any other person. But the question is how do you present that image and how do you break free from the stereotypes and the boundaries in order to allow their excellence to take the natural

course of the milieu of athletic recognition and support in a very competitive world in multiple sports.

Without question disability stereotypes and stigma are strong, particularly in the sporting world. Yet, many of the participants in this study remarked on the potential for their participation in physical activity and sport to change societal views of their abilities. Karen's experience with her friends, who did not support her until after they saw her compete, is a prime example of this effect. Once her friends saw how competitive and serious her sport was, they were eager to contribute to her training. Grant recalled that once his table tennis competitor realized how good he was, after Grant defeated him in the first set, he then had to work hard to compete. It seems that through observing individuals with disabilities participate in physical activity and sport, others can gain a sense of ability that counters the stereotype of someone who is 'disabled'.

Other authors have noted a similar process occurring with participation of other marginalized groups in sport. Among black men, athletic ability has been noted to elevate social status.¹¹⁷ Involvement in physical activity and sport has also been described as lessening the effeminate stereotype of gay men.¹¹⁸ This phenomenon is likely similar for individuals with disabilities and several authors have noted that involvement in physical activity and sport is a possible method of altering the stereotypical image of an individual with a disability.^{113, 119, 120} Taub and colleagues¹¹³ noted that "Through their involvement, individuals with physical disabilities may compensate or demonstrate an alternative image capable of diminishing the effect of a discrediting attitude."^{pg.1482} They expanded further,

noting the potential benefits for the individual with the disability, remarking, "As sport and physical activity is unexpected among individuals with physical disabilities, compensation as a strategy of stigma management may result in a less spoiled identity."^{pg.1482}

Some authors have proposed, however, that this process can be taken too far for those with disabilities, stating that there is a danger in a disabled individual's achievements being regarded as incredible. This type of portrayal, of a disabled individual achieving unbelievable feats, transcending human limitations, and achieving greatly has been referred to as "supercrip" stereotyping.⁷⁸ Although recognizing great achievement is admirable, the creation of a "supercrip" myth has the potential to suggest that individuals with disabilities must transcend their human limitations via extraordinary acts in order to garner respect. This clearly can serve to set an unfair standard for all disabled individuals. In a study by Seymour¹⁰⁷ one individual, herself involved in a great number of sporting activities, reflected this discriminatory attitude, stating, "Anyone in a chair who does not play some sort of sport or do something physical starts to look like a cripple, rather than looking like someone who is disabled."^{pg121} Seymour notes that this type of perception has serious implications for those who can not, or choose not to, participate in physical activity and sport. Clearly, for the individual making this statement, involvement in sport has provided a means of elevating her self identity, yet perhaps not in a healthy way. Hence, although participation in sports by persons with disabilities can serve to assist in dismantling some of the attitudinal barriers in society,

caution must be taken not to create an upper class of elite disabled that are accepted, while leaving others further stigmatized.

The potential for exposure to disabled sport to change the perspectives of disability in society is certainly important to note, however perhaps this exposure can also help individuals with disabilities themselves. Beth, who was self admittedly not happy with her level of activity and wanted to become involved in something, noted that she was excited to see wheelchair tennis on television. She had become involved in tennis just prior to her accident and was despondent that she could no longer participate until seeing a recent report on the news opened her eyes to the possibility of playing again. Describing her amazement in discovering the potential opportunity she stated,

...I didn't even know that you could play tennis if you were in a wheelchair. I just saw that on T.V. ... and I thought 'WOW! Tennis in a wheelchair?! No way!'

Dave too reported being extremely impressed with the athletic abilities of individuals participating in a quad rugby match that he attended, using words like "amazing", "incredible", and "unbelievable" to describe the athletes.

The ability for physical activity and sport to have an influence on perceptions of disability of both individuals with a disability and society at large seems to exist. Witnessing the athletic endeavors of individuals with disabilities has been noted by the participants in this study to have impacted those around them as well as themselves, creating a more 'able' view of those with disabilities. Unfortunately, the primary method of creating exposure in society, the media,

has been found to often create a stereotyped view of sports for individuals with a disability.⁷⁸ In the study of Paralympic coverage by Schell and Duncan it must be also noted that there were instances in which there was empowering portrayals of athletes, and times in which events were covered with a focus on a closely fought contest or the athlete's abilities, much like the Olympics. Also there were instances in which the commentators referred to society as a limiting factor and did not focus solely on the individual and their impairments. This Paralympic coverage reflects the double edged sword that the media can represent to individuals with disabilities participating in physical activity and sport. The media has the opportunity to play a large role in changing societal views of disability, yet the media is also a reflection of the dominant views currently in society and can serve to further perpetuate them.

Without question, the participant's stories in this thesis highlighted the significant impact of the society in which they live on their lives and their participation in physical activity and sport. The social model was found to be a very useful viewpoint through which to observe the struggles of these individuals in becoming physically active after their injuries, highlighting the limitations created and imposed by their society and culture over the limitations created by their impairments. Of note, however, is the internal struggle to redefine self that occurs after injury and its impact on the individual's activity level. Emerging as a surprisingly predominant theme in this study, the described process of redefinition and the role that sport and activity can play is an important sign of the internal struggles faced by an individual after such a life altering injury. At the

same time, it must be noted that the individual's definition of self and acceptance of a new body is largely influenced by the societal ideals by which they are surrounded as well as the social support available, thus implicating a societal role even in this apparently internal struggle.

The men and women of this study certainly demonstrated the complexity of the process of incorporating physical activity and sport into their lives post injury. Their comments highlight the personal and the societal influences as well as noting the complex interactions of the two and temporal influences. Oliver¹²¹ noted the complexities in understanding the experience of an individual with SCI and the need for viewing personal responses in light of the environment.

The experience of SCI, therefore, cannot be understood in terms of purely internal psychological or interpersonal processes, but requires a whole range of other material factors such as housing, finance, employment, the built environment and family circumstances to be taken into account. Further, all of these material factors can and will change over time, sometimes for the better and sometimes for the worse, hence giving the experience of disability a temporal as well as a material dimension.

Hence the personal responses of individuals to their impairments cannot be understood merely as a reaction to trauma or tragedy, nor as a struggle for personal empowerment. Such understandings have to be located in a framework which takes account of disabled people's life histories, their material circumstances and the meaning that disability has for them as they have struggled through collective action to empower themselves and be included in the societies in which they live.^{pg.35}

This study has revealed the diversity of issues faced by individuals with SCI in becoming physically active after their injury and the complexity of the interaction. The participants in this study have revealed physical activity and sport to be beneficial to them physically. More importantly, they have credited it with providing profound meaning to their lives and as a method of contrasting the stigma placed upon them by society, creating a positive identity. With a recognition of the importance of physical activity both physically and psychologically, it is essential that the broader relevance of the stories told by these eight individuals be examined, allowing their valuable insight to be utilized in a method beneficial to all individuals with SCI.

Relevance to Rehabilitation Professionals

Unquestionably, individuals with SCI are not alone in their rehabilitation and they are depending significantly upon rehabilitation professionals to assist them in achieving their goals. Expanded information and a greater understanding of the obstacles faced by individuals in their desire to return to an active lifestyle can only serve to assist rehabilitation professionals in helping our clients achieve such goals. Increased knowledge of which factors contribute to the likelihood of an individual incorporating activity and sport into his/her life after a SCI could assist rehabilitation clinicians tremendously in promoting a healthy lifestyle after discharge, as well as assist in the development of appropriate programs to achieve such goals. In this way, the insightful commentary provided by the eight individuals in this thesis will provide rehabilitation professionals with 'food for

thought' in regards to our current level of care for our clients, as well as in the development of future programs.

A number of crucial issues for rehabilitation professionals arise out of this research that merit attention by those who work with individuals with SCI. Primarily, it is important to recognize the influences of culture, age, gender, race, and other socially related concepts in the lives of our clients. Noting that historically SCI research has limited generalizability outside of the stereotypically young male individual, Krause¹²² discovered that there were notable differences on scores of subjective well-being for individuals with SCI dependent upon their gender, race-ethnicity, and age. As well, differences were observed on career opportunities, finances, and living circumstances scales. Other authors have remarked upon the cultural and ethnic demography of disability^{115, 116} as well as the influences of gender.^{107, 108, 115} Rehabilitation professionals must take into consideration the specific demographic history of their clients and evaluate how it will relate to their interventions.

Another issue of particular importance is the way in which an individual him/herself perceives disability. Many individuals in this study related that their views of disability often stood in the way of their attempting activities and presented a significant hurdle to their acceptance of their injury. Through a knowledge of the clients' perspectives of disability, and a recognition of the societal influences on that perspective, a rehabilitation professional is better able to address any misinformation or mistaken ideas of their abilities and opportunities. This process may be inherently difficult given the time an individual

spends in rehab and the time it may take for the individual to understand the meaning of disability for them. Participants in this study related that the process of redefining self and the meaning of disability was, for some, long. Regardless, knowledge of the individual's views of disability at the time would still be of great value to the rehabilitation professional.

This study has revealed the process of rediscovering and redefining self that occurs after an injury. Certainly, as rehabilitation professionals, it is a goal to assist individuals to return to as many of their previous roles as they are able. Some authors have suggested that rehabilitation, with its focus on the physical environment, has neglected the larger issues faced by its clients. Williams¹²³ remarks upon the different approaches to defining the environment:

Within rehabilitation, the environment has been defined for the most part as a physical phenomenon, a set of discrete obstacles or barriers, which add to and amplify the problems of impairment afflicting individuals. Within disability theory, the environment is regarded as the expression of power, a universe of discrimination and oppression within which disability is created. The sociological study of chronic illness and disability has tended to define the environment as something arising out of the symbolic and social interaction that takes place between individuals and their worlds as they negotiate their everyday lives.^{pg195}

Regardless of the specific academic doctrine that one follows, this study has presented the environment as much more than simply physical. The individuals in this study remarked upon the influences of the society around them in both enabling and disabling their participation in activities. It is imperative that

as rehabilitation professionals, we are aware of both the enabling and disabling influences in society so that we are more knowledgeable and better equipped to assist our clients in achieving their goals.

It is important, not only that we recognize and help prepare our clients for the attitudinal barriers that they will face in society, but also that we be cognizant of the influences of our own attitudes and actions. Nicole remarked that when she was in rehabilitation she found that her therapist greatly underestimated her abilities and passed these lowered standards on to her. It was only through self-discovery that Nicole found her true potential and discovered that she could participate in a sport that she truly enjoyed. As rehabilitation professionals we must, therefore, question ourselves as to our own perceptions of disability and observe how these views can either encourage or discourage our clients. The point of client centred practice is that rather than letting our perceptions influence our client's choices, it is our responsibility to help them find ways to realize their aspirations; encourage them to set the priorities. We must ensure that we are not a barrier to their participation.

Relevance to Those Planning Physical Activity and Sport

The stories told by two individuals in this study in particular appear to highlight a dire need for a better distribution of resources and information. Beth, five years after her injury, reported a substantial desire to find a sport or physical activity to become involved in. She was not happy with her physical, or emotional, condition and recognized that participation in physical activity, much a

focus in her life prior to her injury, would be of great benefit. Yet during the entire interview with the researcher, while expressing a desire to participate, Beth repeatedly asked, "what can I do?", reporting a lack of knowledge of the opportunities that existed for her. Karen described a specific time in which she sought out assistance on modifying the seating of a kayak with no success. Some time later, by accident, she discovered there was a kayaking program for individuals with disabilities in her area all along, which was actually in jeopardy of having its funding cut. These stories highlight the importance of increasing awareness and knowledge of what is available in the community for individuals who want to become physically active. Resources are only helpful if they are known of.

Some individuals in this study, however, related that especially in more recent times, individuals in rehabilitation are presented with a great deal of information and introduced to sports very early on. Why then, would this apparent discrepancy exist? There are likely two reasons, which were emphasized by the participants in this study. One factor is likely location, both geographically and in time. Individuals injured many years ago are less likely to have had the same degree of recreational opportunities presented to them during their rehabilitative stay. As well, although those now attending rehabilitation in Vancouver do have opportunities for participation in physical activity and sport early on, this may not be the case for those in smaller communities or even in other communities around Canada and the United States. A second factor that must be considered is the timing with which these programs are introduced. Rehabilitation times are

shortening in recent years with health care funding decreasing and approaches to treatment changing. During the short time in rehabilitation, physical activity and sport are but a small fraction of the issues to be addressed. For most individuals in this study, there was a significant period of time during which larger issues were of primary importance and the main goal was just to progress out of rehab and reestablish themselves and their lives. Although for some, physical activity and sport were described as methods of reestablishing a positive identity, for others it was not until years later that physical activity and sport became a priority. It is at this point that the resources and opportunities are needed, as well as the knowledge of where to turn for information. Therefore, it is important that we consider the timing and structure with which physical activity and sport are presented to individuals with SCI.

The individuals in this study also highlighted the numerous factors other than their impairments that limited their participation in physical activity and sport. From a lack of appropriate equipment, to a fear of the attitudes of those watching, and even their own views of disability, this study has described the complex issues faced by individuals with SCI. Programs that make equipment available for use appear to overcome a large barrier, enabling individuals to experience a sport without having to commit large amounts of time and money prior to even experiencing it. Addressing the larger issues of attitudes towards disability is perhaps a much more complex issue. Many participants stressed the feeling of self-consciousness that they experienced when active in front of others. This is certainly a consideration in an integrated setting. Grant noted that in such

a setting he was "continually reminded of what [he] could no longer do." Yet, not being integrated with the able-bodied leads to segregation and the potential for a further promoting of stereotypes and stigma. Certainly, a consideration of the degree of integration and the timing of such actions is warranted. Many individuals remarked on their increased comfort with others in wheelchairs when first in rehabilitation and the profound self-consciousness that they experienced once returning to the community. Hedrick⁵¹, in a study of wheelchair tennis participants noted that individuals with disabilities faced increased anxiety when in an integrated setting, much as described by Grant. It was felt that a gradual progression to integration provided the best results. Perhaps a gradual progression towards integrated activity is required in order to maintain comfort levels at first, but prepare the individual for the realities of the social world.

Three of the participants in this study related that their introduction to physical activity and sport was through a role model in a wheelchair, providing them with a viewpoint with which they could identify. Programs that provide such role models perhaps create a non-threatening, less intimidating way of beginning by eliminating the inherent power differentials present when physical activity and sport are presented by able-bodied rehabilitation professionals and other agencies. As well, through another individual who faced similar concerns and questions at an earlier time, comfort may be increased and potential opportunities presented in a more relevant and realistic fashion.

For a number of individuals with SCI, their own views of disability, stemming from the culture around them, are limited and uncertain and may serve

to limit their personal expectations. Individuals in this study described being completely uncertain of their abilities and opportunities after their injury, as well as uncertain as to whether or not they could ever regain the feeling of being an athlete again. For many of the participants in this study, it was only when they were visited by a friend or role model with a similar disability that introduced them to possibilities for activity that they thought about the potential. Karen, Grant, and John all recounted anecdotes of visits by others that began to open up their eyes to the possibilities. This initial visit may not be enough however, and a number of participants described becoming involved in physical activity through a gradual exposure. For some, beginning as a trainer or assistant for a team later grew to further involvement through sparking a renewed interest in athletic endeavor. For others small, informal activities grew into athletic competition. Events in which participants were able to experience sport informally, with access to both equipment and role models, were reported as an effective method of providing this gradual exposure to the opportunities and potential existing.

Regardless of the path taken by each individual, it is apparent that there are a number complex issues to be considered when planning physical activity and sport for individuals with SCI. Of prime importance is a recognition and consideration of these issues, in order to provide individuals with rich and fulfilling opportunities to incorporate physical activity and sport into their lives.

Relevance to Friends and Families of Those with SCI

Individuals with SCI are rarely on their own when recovering from an injury and certainly the family and friends of an injured individual play a role. Studies have found that after SCI, the degree of social support available is crucial, with higher levels of social support leading to decreased levels of depression ⁴⁵, and social support being positively linked to both life satisfaction and physical well-being.¹²⁴ The eight individuals in this study reinforced the importance of social support, with almost all individuals relating significant roles played by friends and families in helping them become involved and maintain involvement in physical activities through providing emotional support and encouragement. Almost every participant noted that they receive a lot of encouragement by family or friends to participate in physical activities and sport. Mark described the support he receives from his family as "phenomenal" reporting that they have always encouraged him to do whatever he would like. For a number of the participants, one individual in particular was singled out as providing the emotional support and assistance to get involved in physical activities. John, although having a negative experience with a previous friend who could not accept his injury, was drawn into an active lifestyle through wheelchair racing by a friend he had met in rehabilitation. He credits this individual for giving him the motivation to try the activity and the support he needed to train. Nicole also notes that she has one friend who stands out from the others, by assisting her in finding activities to participate in and participating in activities with her. Grant recalls a coach in the community that he returned to after rehabilitation as being a motivating and

encouraging figure that helped him to realize that he could be an athlete again. These testimonies certainly highlight the profound impact that the encouragement and support of even one individual can have.

Although it must not be overstated, the results of this study can also have an impact beyond the lives of those with SCI and those immediately surrounding them. In fact, the insights provided by this study could have an influence on society at large. Central to this thesis is the recognition that society has a definite influence on disability. Therefore, any change in societal attitudes can be profound. The results of this study may promote a greater appreciation of the physical activity and sport needs of individuals with SCI, thereby improving the social atmosphere in which individuals with SCI face the majority of their barriers.

Relevance for Policy and other Community Issues

All of the individuals participating in this study reported having support from family or friends. This support has been noted to have been invaluable. However, few individuals could successfully become involved in physical activity without another form of support. Equipment for participation in physical activity and sport, such as a hand cycle, was noted earlier to be extremely expensive and beyond the financial reach of many. This was echoed by participants in this study, with Karen and John reporting that they received their sports wheelchairs through other means. John had a chair donated through a charitable organization and Karen received financing through an insurance company. Even in Karen's case, gaining funding was not easy and she reported having to argue with the

insurance company for some time to plead a case as to why she required a specialized chair. Funding sources become a big issue when purchasing equipment for sporting activities as they are often considered luxury items and unnecessary for the individual. Insurance, workers compensation, and other sources of funding often consider physical activity and sport as a frivolous expense and securing funding for such expenses can be difficult. The policies in place are perhaps even based on the stereotyped views of individuals with disabilities as unable to participate in meaningful physical activity. Studies, such as this current one, that highlight the tremendous potential of physical activity and sport can assist in providing evidence to support the need for policies that enable individuals access to needed equipment.

The issues are likely magnified for those individuals without immediate access to support, those who live alone and those who have little or no family support. For these individuals, the reliance upon socially structured programs and benefits is even larger.

Through studies such as this one, policy makers and organizations can be provided with evidence of the importance of physical activity and sport for individuals with SCI. This increased knowledge can provide an impetus for policy changes that provide improved access to the necessary specialized equipment.

Relevance to Those with SCI

Most importantly, the stories told by the eight men and women in this study hold meaning for those who will follow. After sustaining such a life altering

injury, individuals with SCI are faced with a tremendous amount of change in their lives. The magnitude of this change is described by all eight individuals in this study, relating that the injury had a large and significant impact on their lives. For all individuals, and particularly for those trying to reincorporate a previous focus on physical activity, there is a great deal of uncertainty and unfamiliarity. The more information that these individuals have regarding their situation, the better equipped they will be to navigate their way through recovery. The stories of the men and women in this study can assist newly injured individuals through an illumination of the issues which they are likely to face, and highlighting both successful and unsuccessful methods of incorporating physical activity and sport into their lives.

Through the words of the eight participants, this study has served to confirm the potential importance of physical activity and sport in an individual's life post-injury. Other authors have found that satisfaction with leisure corresponds with life satisfaction¹²⁵, and that recreation and sport provides both physical^{25, 35, 39-44, 126} and psychological⁴⁸⁻⁵¹ benefits. The participants in this study certainly confirmed these findings stating that they experienced physical benefits from activity as well as an overall sense of well being. As well, they related that physical activity and sport provides a tool for overcoming the loss of identity that occurred after injury and redefining themselves in a positive and healthy way. For two of the participants, physical activity and sport was part of 'cleaning up their lives' in their battle against drug addiction. For others facing the struggles of redefining themselves and their lives after injury, and particularly those for whom

physical activity represented a large part of their life prior to injury, physical activity and sport should be considered as one way in which a positive identity can be developed. The individuals in this study also recognized that other activities such as school, work and other hobbies could also serve a similar purpose.

Limitations of the Study

As with any research, there are limitations to this study and the conclusions made. Primarily, the size of the sample must be considered. This study consists of data gathered from the comments of eight individuals. This is a small group when compared to the population of individuals with SCI and therefore the results cannot be generalized to others blindly. However, this study does not intend to be statistically representative of the SCI population but instead to provide insight into a complex process. The experiences of these eight individuals may ring true for others with SCI and provide much needed insight for rehabilitation professionals and others working with individuals with SCI.

The experiences presented in this research are all relating to individuals living in the lower mainland of British Columbia and as such the degree to which their experiences correlate with the experiences of those in different locales is questioned. This particularly applies to insights of societal structure and its influence on the participants. However, others can still gain valuable, pertinent knowledge through seeing where the participants in this study blamed or applauded society, regardless of one's particular location.

As well, all of the participants in this study are paraplegic. As such this research, although perhaps hinting, does not provide a sufficient view of the experiences of those with tetraplegia. This may be a direction for future research to explore. Similarly, this study may provide a template for investigations of other populations of individuals with impairments.

The data gathered for this research consists of the transcripts recorded from only one conversation with each participant, as well as follow up telephone conversations with three participants. In this way, the data is limited to some degree by the participant's memory of events and history on the day of the interview. Also, as noted in Chapter Three, the data is limited to some degree by the biases of the researcher and this must be acknowledged. Even through pursuing a particular topic, the researcher demonstrates an interest, and consequently a bias, towards the subject. In this study, as remarked on in Chapter Three, methods have been employed to reduce the amount of researcher bias and make inherent bias transparent.

Applications for Future Research

This study, being more of an exploration than an examination, has likely created more questions than it has answered. It was designed to uncover the issues faced by individuals with SCI in incorporating physical activity and sport after their injury and it has revealed that the issues are multi-faceted and complex. It is important to consider from where research can go with consideration of the discoveries of this study.

Of primary importance is a consideration of the current structure of rehabilitation and community programs. Some of the experiences and comments of the individuals in this study question the efficiency and impact of available resources in enabling participation in physical activity and sport post injury. Future research could investigate how rehabilitation programs and community based associations structure their programs to ensure clients receive appropriate opportunities for participation in physical activity and sport. As part of this, and in recognition of the finding that the adjustment process is complex and dynamic, studies could investigate the most appropriate timing for intervention. Perhaps interventions in the first few months after injury are not as well received in the midst of the larger issues that an individual is facing.

The process of redefining self and the role of physical activity and sport as a vehicle through which individuals can achieve a positive self-identity is also worth studying. As a part of this, a 'chicken or egg' type of question must be addressed. Are physical activity and sport helping to achieve a positive self-image or is a positive self-image encouraging participation in physical activity and sport? The role of family members, friends, and even rehabilitation professionals in assisting or discouraging the implementation of physical activity and sport into one's life is also an area of interest.

As this study discovered the issues to be multi faceted and complex, a number of more specific questions could be developed to explore demographic factors, such as age, time since injury, ethnicity, or gender on involvement in sport.

Future studies could perhaps extend the direction of this research through changes such as a greater number of participants, or a number of interviews over time with the participants. This would allow for more in-depth analysis of the important issues arising from this research.

Concluding Thought

Both Karen and John, during their interviews, described their wish for a 'dream center' for individuals with SCI, as well as those with other disabilities and able-bodied individuals. They remarked that this dream center would be a place in which accessibility was not an issue, nor were finances, or feeling self-conscious. They described it as having a number of opportunities for physical activity, with a variety of equipment and programs. As well, they envisioned resources available to answer questions and provide support. Perhaps this 'dream center' does not have to represent an actual facility. Perhaps it could be viewed as a metaphor for society. Their dream center really represents what society must provide in order to allow individuals with SCI to experience a myriad of opportunities in physical activity and sport, providing access, support, and opportunity in an inclusive and accepting way.

It has already been noted that this study may have created more questions than it answered. This may be true, but if this is the case then it has served its goal. Through shedding light on the diverse and complex reality that faces individuals with SCI in trying to incorporate physical activity and sport into their lives, this study provides those individuals, their families and friends, and

rehabilitation professionals with a greater understanding of their needs. It is only through this greater understanding that we can move forward to address the issues and enable individuals with SCI to have opportunities in physical activity and sport that can provide them with improved health as well as create a full and meaningful life.

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APPENDICES

APPENDIX I

PARTICIPANT DEMOGRAPHICS

Participant Name	LEVEL OF INJURY	TIME SINCE INJURY (YEARS)	EMPLOYED	ACTIVITY LEVEL
Adam	LOW PARA	27	YES	Swim 2x/ week Member of w/c athletics team Has tried many activities including sailing, scuba diving
Beth	T1	6	NO	Very little activity Some wheeling in neighborhood
Dave	T8 incomplete	2	RETIRED	Pool exs 3x/week Gym (weights) 3x/week
Grant	T10	27	YES	Was competitive athlete in w/c sport. Now activity is focused on recreation and fitness. Wheeling, hand cycle, pilates
John	T4	9	NO	Weightlifting, wheelchair racing, hand cycling
Karen	T4	27	NO	Was in competitive w/c sport as teen. Now involved in a number of recreational activities. Hand cycling, kayaking, wheeling,. Has tried other activities such as water skiing, climbing
Mark	T7-8	22	YES	At first inactive x 5 years. Now, recreational activity. Hand cycling with family, wheelchair basketball on fairly regular basis
Nicole	T4-6	10	YES	After injury, swimming in home pool. More recently involved in number of recreational activities: hand cycle, kayak, wheeling

APPENDIX II
LETTER OF INVITATION

To whom it may concern,

I am a graduate student in the School of Rehabilitation Sciences, in the Faculty of Medicine at UBC. I am currently conducting a study to explore the issues around involvement in physical activity and sport after a spinal cord injury from the perspective of spinal cord injured individuals. The study, which is research for my graduate degree, is entitled "Physical Activity and Sport after Spinal Cord Injury: An Inside Perspective". The purpose of this study is to uncover the issues relevant to those with spinal cord injuries regarding participation, or lack of participation, in physical activity in the form of sport and physical fitness.

There is very little information on what factors prompt some people to become involved in sports and physical activity after a spinal cord injury and what factors prevent others. My research is designed to develop an understanding of these issues constructed from the perspective of those who are in a position to know.

The research would involve giving me an opportunity to discuss your experiences and feelings about sport and physical activity after a spinal cord injury with you in an interview. Interviews would take place in the location of your choice at a time that is convenient for you. I anticipate that only a single interview will be required, lasting for approximately one hour. This time could be adjusted to suit your needs. With your permission, in order to avoid slowing the spontaneous nature of the discussion, the interview will be recorded to audiotape and transcribed at a later time.

All information, recorded or verbal, will be kept strictly confidential, and no information that could identify you or any member of your family will be included in the final report. All data will be destroyed once the final report is completed. You will be given an opportunity to review a record of your comments if desired and you also may request a copy of the final report.

In order to share my findings with others, my research findings will be submitted to academic journals and also newsletters and magazines relevant to those with disabilities. Once again, I want to reassure you that no person will be identifiable by these reports.

You have the right to withdraw your participation at any time and can decline to answer any question. There will be no repercussions from doing so and it is your right to do so at any time. No official agency will be aware of your participation or be able to identify you in any way.

If you have any questions at this time or during the research, please feel free to contact my supervisor, Dr. Darlene Redenbach, Assistant Professor, School of Rehabilitation Sciences, at the University of British Columbia, (604) 822-7611.

If you would like to participate, please contact Dr. Redenbach at the above number and an interview time will be arranged. Thank you for taking the time to consider participating in this study.

Yours sincerely,

Stephen Levins

M.Sc. Candidate

School of Rehabilitation Sciences, Faculty of Medicine, UBC

APPENDIX IV
QUESTION CHART

<p style="text-align: center;">PAST</p> <ul style="list-style-type: none"> • Injury / rehabilitation • Activities • Location (where) 	<p style="text-align: center;">FUTURE</p> <ul style="list-style-type: none"> • Plans / Goals Fitness & Otherwise
<p style="text-align: center;">SELF</p> <ul style="list-style-type: none"> • Feelings re: disability /disabled sport & fitness / adaptations • Self concious • Identity • Knowledge of opportunities / awareness • Definitions of physical activity 	<p style="text-align: center;">SOCIETY</p> <ul style="list-style-type: none"> • Barriers Physical Attitudes The System • Views re: Disability / disabled sport • Gender • Support / Resources - family, friends, organizations
<p style="text-align: center;">ACTIVITIES</p> <ul style="list-style-type: none"> • Typical Day • What, where, when, how • WHY • -benefits of • WHY NOT 	