

THE MEANING OF TRANSITIONING FROM
REHABILITATION TO A PHYSICALLY ACTIVE LIFESTYLE
FOLLOWING A SPINAL CORD INJURY

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ABSTRACT

This study explored the meaning people with spinal cord injuries give to physical activity and recreation participation as they make the transition from the protected environment of hospital rehabilitation to the reality of returning to their homes and communities. The experiences of 4 individuals between 15 and 24 years of age who had sustained spinal cord injuries within the previous five years were captured using the phenomenological methods of semi-structured individual interviews, focus group interviews, photographs, and field notes. Rimmer's (1999) model of health promotion for people with disabilities combined with Peters (1996) model of disablement provided the conceptual framework for the study and facilitated the interpretation of the findings. The participants indicated that physical activity was a very important component to living a psychologically, socially and physically healthy lifestyle following a spinal cord injury. A thematic analysis revealed three themes: (a) as my body heals, (b) learning to be me, and (3) getting back to life. The importance of physical activity in maintaining a healthy lifestyle following a spinal cord injury was reflected in stories of physical activity as a component of hospital rehabilitation, the importance of physical activity during the transition from the hospital to the challenges of returning home, and finally, engagement in community based physical activity. A gap in the continuity of physical activity opportunities during the transition from in-hospital rehabilitation to the return to the community was identified.

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1.0 INTRODUCTION

1.1 Letter to Participants

Dear Participants,

As I reflect on the time we have spent together, I am humbled by the significant role each of you played in this research study. I would like to take this opportunity to express my sincere gratitude for all of your assistance. Without your open willingness to participate and share your stories, I would not have gained such a deep and meaningful understanding of your physical activity experiences following your spinal cord injuries.

As I listened to each of you recount your rehabilitation experiences, I was reminded of how crucial the rehabilitation process is for someone who has sustained a spinal cord injury. I believe rehabilitation is a unique journey that no one can fully understand or appreciate unless he or she has experienced it. The sharing of your experiences will provide others with the opportunity to gain a small glimpse into what rehabilitation and the return to a physically active lifestyle following a spinal cord injury is really about. Adjusting to life after an injury of this nature does not just “happen” following discharge from the rehabilitation hospital. Reintegration into life takes time and dedication.

As someone who has also gone through the rehabilitation process, I feel honoured and moved that you were willing to share your rehabilitation experiences with me. Because of your willingness and ability to share such in-depth stories about your experiences I feel that you deserve credit and recognition as co-researchers, and I thank you for the time, effort, and energy you provided.

Respectfully

Paul Gustafson

1.2 A Personal Interest

In 1984, at the age of 17, I sustained a spinal cord injury resulting in quadriplegia and a six-month stay at a rehabilitation hospital. Prior to my injury, I had always been active in sports and physical activities. Following my spinal cord injury, it was difficult to maintain that same level of physical activity as I had prior to my injury. I found myself focusing more on my education and employment opportunities, and less on sport and physical activities. I did not return to a physically active lifestyle until 5 years following my spinal cord injury. At that time I slowly became involved with wheelchair sports as a recreational athlete, playing wheelchair rugby and participating in alpine skiing. My return to physical activity was invigorating and energizing.

My renewed interest in physical activity was inspired in part by my professional work experience as a Rehabilitation Counsellor and Sports Development Coordinator for people with spinal cord injuries. It was also inspired by my personal experience with a spinal cord injury. As a Rehabilitation Counsellor and Sports Development Coordinator I was a member of various rehabilitation teams that focused on assisting patients with spinal cord injuries return to their families and communities. I also became interested in the effect that physical activity had on the rehabilitation process. My personal experiences helped me to understand the potential psychological, social, and functional benefits of physical activity for people who were coping with the trauma of a spinal cord injury. I have continued to advocate for and promote physical activity for people with spinal cord injuries, through my employment and personal networks.

In 2001, I was invited to join Dr. Goodwin's research team at the University of Saskatchewan, immediately becoming involved in two research projects *Daddy's Broken: Perceptions of Physical Well Being by Men with Disabilities*, and *Reactions to the Metaphors of*

Disability: The Mediating Effects of Physical Activity. I was integrally involved in all phases of the research process, including participant recruitment, research question development, sampling strategy development, data collection method determination, data collection, and interpretation of the findings. As Dr. Goodwin's research program focused on physical activity and recreation experiences of people with disabilities, I was able to expand my knowledge in this area.

My personal and professional experiences have enriched my understanding of the benefits of physical activity and stimulated my interest in exploring physical activity and quality of life for people with spinal cord injuries. This experience inspired me to pursue graduate studies and explore the importance of physical activity experiences of people with spinal cord injuries. More specifically, I was interested in the meaning people with spinal cord injuries gave to physical activity as they transitioned from the protected environment of hospital rehabilitation to their homes and communities. The participants of my study generously shared their personal stories of their experiences with spinal cord injury, rehabilitation, and physical activity.

I believe that exploring the participants stories will deepen our understanding of how creative and innovative approaches to rehabilitation and physical activity can promote a smooth and positive transition from a rehabilitative hospital setting back into the community setting for people with spinal cord injuries.

2.0 LITERATURE REVIEW

2.1 The Benefits of Physical Activity

Spinal cord injuries occur when the spinal cord suffers direct irreparable damage from an injury or medical condition (Figoni, 1997). Each year in Canada as many as 1050 people sustain spinal cord injuries resulting in permanent paralysis with a loss of body function and movement (Canadian Paraplegic Association, 2000; Figoni, 1997). People who sustain spinal cord injuries are often hospitalised for up to six months, with much of this time being spent in rehabilitation (R. Griebel, personnel communication, September 18, 2003). While in rehabilitation, the individual with a spinal cord injury will see many professionals, including occupational therapists, physical therapists, and therapeutic recreation specialists (Hutchinson & Kleiber, 2000). Although each of these disciplines specializes in specific therapy modalities, they are linked together by movement as it provides the foundation of their professional practice. Each therapeutic discipline works closely together to assist the individual with the spinal cord injury become as independent as possible with the aim of returning home (Johnson, Wood, & Fiedler, 2003).

It has been estimated that 56% of Canadians with impairments are not physically active (Martin Ginis & Hicks, 2007) and only 10% may be active enough to receive measurable benefits from their participation (Rimmer, 2005). This high level of physical inactivity may be due, in part, to a gap in service provision following an injury as people transition from rehabilitation settings to community based wellness programs (Rimmer, 2006). In response, rehabilitation personnel actively engage in post-discharge transition planning to assist families coordinate and access many community services including opportunities to participate in physical activity (Turner, Fleming, Ownsworth, & Cornwell, 2008). Even in light of well

designed and implemented transition plans, individuals can be faced with under-trained staff, physical obstacles, and exclusionary policies (Bedini, 2000; French & Hainsworth, 2001; Rimmer, Riley, Wang, & Rauworth, 2005).

Inactive people with spinal cord injuries increase their risks of acquiring a number of secondary health conditions that may result in a decline of functional capacity and quality of life (Rimmer, 1999). Functional capacity refers to the functional ability someone has after sustaining a disability such as a spinal cord injury, or someone's ability to function at the capacity allowed him or her due to his or her disability (Rimmer, 1999). Physical inactivity places people with spinal cord injuries at risk of decreased function due to fatigue, skin breakdown, decreased circulatory and internal systems functioning (Kavanagh & Shephard, 1990). Other secondary conditions, which may result from a lack of physical activity, include obesity, diabetes, heart disease, osteoporosis, and respiratory problems (Carlson, Ostir, Black, Markides, Rudkin, & Goodwin, 1999). Therefore, the decreased ability to function is a serious problem for people with spinal cord injuries who are inactive. Physical activity may help to prevent these disabling secondary conditions for people with spinal cord injuries (Rejeski & Focht, 2002).

Using myself, a C5-6 quadriplegic as an example, my functional capacity includes my ability to push a manual wheelchair independently as I have some function of my upper arms. I do not have function of my triceps, full wrist flexors, or lateral muscles; therefore my upper body function is limited. Without daily physical activity, the function I do have in my upper body and respiratory system would decrease to a point where I may be unable to manoeuvre a manual wheelchair independently and create problems including muscle and respiratory fatigue, which may lead to increased health concerns including skin breakdown and decreased circulatory function.

People with spinal cord injuries who participate in physical activity have reportedly improved their physical function and psycho-social health (Ashton-Schaeffer, Gibson, Autry, & Hanson, 2001; Carlson, et al., 1999; Henderson & Bedini, 1995). Yet persons with spinal cord injuries are conspicuously absent from community fitness and exercise facilities (Rimmer, 2005). The psycho-social benefits of physical activity for people with disabilities include: (a) enhanced self-esteem (Hutchinson, Loy, Kleiber & Dattilo, 2003; Kleiber, Hutchinson, & Williams, 2002; Kosma, Cardinal, & Rintala, 2002), (b) reduced clinical depression, improved family and social interaction (Loy, Dattilo, & Kleiber, 2003), (c) prolonged life expectancy (Finley Rodgers, & Keyser, 2002; Lannem, Sorensen, Frosli & Hjeltnes, 2009; Sheng & Williams, 2000), (d) enhanced quality of life (Bedini, 2000; Kleiber, Brock, Youngkhill, Dattilo, & Caldwell, 1995; Kleiber, Hutchinson, & Williams, 2002; Tate, Kalpakjian, & Forchheimer, 2002), (e) a sense of belong to a community (Carpenter & Clark, 1994; Dattilo, Caldwell, Youngkhill, & Kleiber, 1998; Goodwin, Johnston, Gustafson, Elliott, Thurmeier, & Kuttai, 2009; Levins, Redenbach, & Dyck, 2004; Sheng & Williams, 2000), and (f) enhanced body image (Basset & Martin Ginis, 2009).

Vissers et al. (2008) in their study of the barriers and facilitators of physical activity for persons with spinal cord injuries following discharge from rehabilitation found the three most important barriers to participation in physical activity were building accessibility, physical health problems and mental health concerns. The three most important facilitators to participation were preparation in the rehabilitation centre with respect to physical activities, stimulation in the rehabilitation centre to be physically active, and preparation for social activities. The authors also reported that support from friends and family was the most frequently mentioned facilitator to physical activity shortly after discharge. Vissers et al. (2008) found that shortly following

discharge, problems with self-care and movement in and around the house were relatively important to the participants, as were their feelings of sadness. Additional implications for participation following discharge included lack of their own transportation, equipment, stimulation from family to be active, and attention to physical and mental health concerns.

The importance of movement about the house following discharge from rehabilitation was also noted by Van den Berf-Emons et al. (2008) who found a marked decrease in the level of physical activity of 40 people with spinal cord injuries from their inpatient rehabilitation levels. The decline was felt to be reflective of the lack of mobility aides (equipment) and home renovations (accessibility) at the time of discharge. It was noted that at one year following discharge the physical activities level were restored to discharge levels. The authors concluded that behavioral strategies to support physical activity patterns should start as early as possible in rehabilitation to overcome barriers related to physical accessibility and lack of proper mobility aids.

Loy, Dattilo, Kleiber, & Hutchinson (2002) investigated the presence of leisure patterns of those with and without depression symptoms after spinal cord injury. As sadness and depression can be a negative outcome of spinal cord injury, the authors looked at the relationship between participation in 20 specific leisure activities and symptoms of depression in 178 adults. They concluded that there was a negative relationship between depression symptoms and 18 of 20 selected leisure activities. Among the 18 activities were such pursuits as board games, traveling, computer activities, billiards, fitness, and movies.

The social and psychological effects of disability were highlighted by Gill (1997) in her discussion of integration and disability identity development. Gill (1997) discusses how individuals with disabilities strive for integration within themselves and within society, searching

for individual acceptance and a sense of community. Striving for integration creates ‘twin pulls’ as the individual begins to claim his/her own identity as a person with a disability while simultaneously attempting to assimilate into society (Gill, 1997). Discovering one’s own identity and attempting to ‘fit into’ society as an individual with a disability is a process that people with disabilities undergo as they create a disability identity. Gill (1997) purports that disability identity development includes ‘coming together,’ ‘coming home’ and ‘coming to feel we belong’. Coming together represents the internalized acceptance of the impaired aspects of the body as integral to the sense of self. ‘Coming home’ gives people with disabilities permission to share common lived experiences with others who ‘have been there’ and promotes increased self-esteem and a sense of belonging to a community (Gill, 1997). ‘Coming to feel we belong’ addresses community integration into society as a whole as an individual with a disability.

Levins et al. (2004) reported “loss of an able identity: who am I?” (p. 501) in their qualitative study that explored the physical activity experiences of 8 adults with spinal cord injury. The participants reported missing their previous lives and that the process of reaffirming their new sense of self was difficult. Physical activity played a role in their lives post injury and was an integral part of re-establishing life.

The physical and functional benefits of physical activity for people with spinal cord injury include (a) increased physical strength, increased cardio vascular fitness, increased circulation and skin health (Carlson, et al., 1999; Finley et al., 2002; Harvey, Glinsky & De Wolf, 2009; Kavanagh & Shephard, 1990; Rimmer, Braddock, & Pitetti, 1996; Sadowsky & McDonald, 2009; Shephard, 1991), (b) decreased obesity and respiratory illness (Fernhall, Heffernan, Young Jae, & Henrick, 2008; Rimmer, 1999), (c) lowered risk of diabetes (Cooper et al., 1999; Rejeski & Focht, 2002), and (d) increased physical function to complete activities of

daily living (Carlson, et al, 1999; Hetz, Latimer, & Martin Ginus, 2009; Kloostermna, Snoek, & Jannink, 2009; Rimmer, Braddock, & Pitetti, 1996).

Low physical activity participation among people with disabilities is a complex issue that includes physical, social, and attitudinal barriers as well as internal motivation (Henderson & Bedini, 1995). In summary, barriers to physically active lifestyles include a lack of physical accessibility to leisure facilities and a lack of accessible fitness equipment within leisure facilities (Bedini, 2000; Carpenter, Forwell, Jongbloed, & Backmen, 2007; Liang et al., 2008). Additional challenges include a shortage of wheelchair accessible transportation to move individuals to and from facilities, under-trained staff and program personnel, and negative societal attitudes towards physical activity participation opportunities for people with disabilities (French & Hainsworth, 2001).

2.2 Health Promotion for People with Disabilities

Historically, service provision for persons with disabilities has been guided by the medical model, with the assumption that disability resulting from a change in bodily functions or structure left a person vulnerable, weak, and in need of ongoing care, often within the medical system (Fine & Asch, 1988; Taleporos & McCabe, 2002). An illness or sickness metaphor was therefore associated with disability suggesting that medical intervention may lead to a cure (French & Hainsworth, 2001). If the illness could not be cured, the individual was perceived to be unhealthy and incapable of returning to their none-ill state (Younghill, Dattilo, Kleiber, & Caldwell, 1995). The “illness” label therefore omitted persons with disabilities from public health promotion initiatives that promoted physical activity as means to promote health (Kosma et al., 2002), thereby further perpetuating the illness metaphor.

Fortunately, the medical model has been broadened to include environmental and socio-cultural impacts on health (Peters, 1996). In recent years, health promotion initiatives have begun to include people with disabilities in their campaigns acknowledging that people with disabilities can be healthy and lead physically active lives (Rimmer, 1999). Unfortunately, the message of physical activity as a health benefit has not, as of yet, had a significant impact on the disabled community as there continues to be a very low percentage of people with disabilities who participate in physical activity on a regular basis (Kleiber et al., 1995). For example, an individual with a spinal cord injury who has been receiving in-hospital physical therapy through rehabilitation services may be discharged from the rehabilitation setting without physical therapy follow-up services or connections to disability physical activity or sport programs in the person's home community (Rimmer, 1999).

Rimmer (1999) recognized the importance of health promotion for persons with disabilities. He presented a model that advocates for a seamless transition of services from hospital rehabilitation to clinically supervised fitness facilities to community fitness centres. In doing so, strong linkages between physical therapy in rehabilitation facilities and a focus on fitness in community based fitness facilities is required (see Figure 2.1).

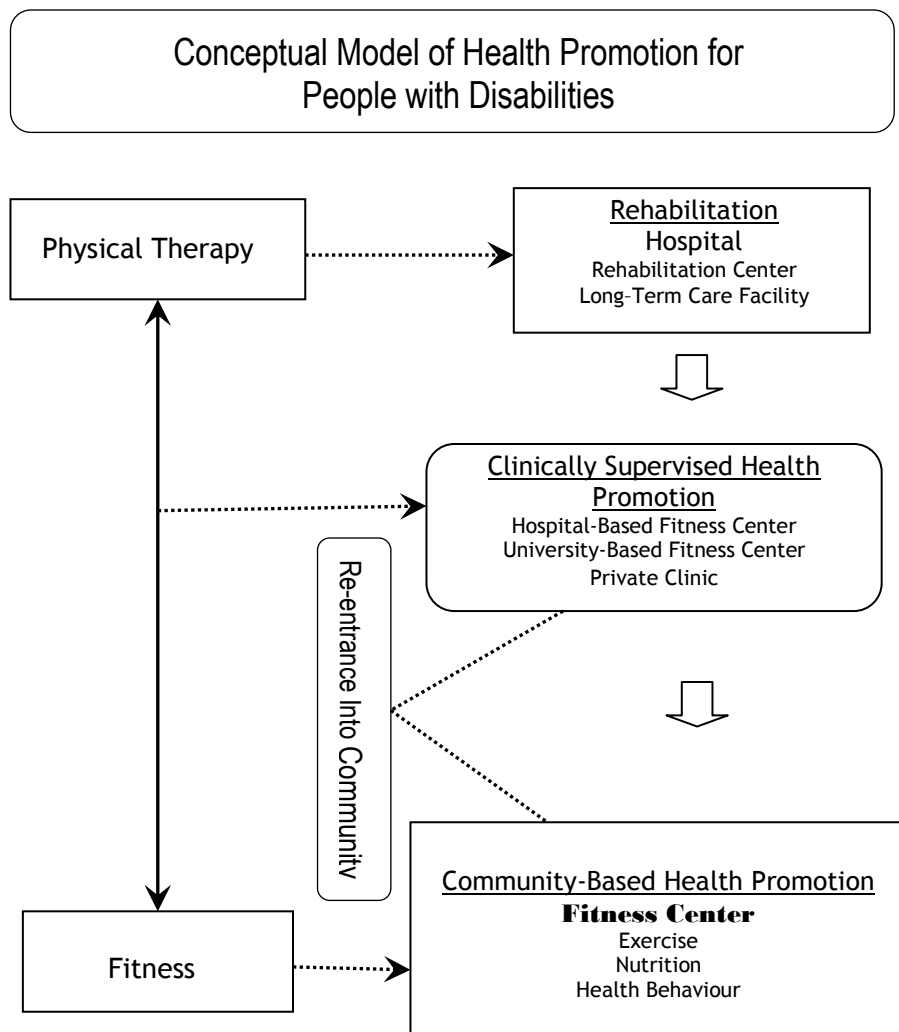


Figure 2.1. Health Promotion Model for People with Disabilities (Rimmer, 1999)

Rimmer’s (1999) model suggests that people recovering from spinal cord injuries should have the option to continue their rehabilitation programs in supervised clinical settings in preparation for a healthy and fit lifestyle in a community environment. He further advocates for a comprehensive transition plan for people with disabilities as their rehabilitation, health, and fitness needs change. Ultimately, the aim of Rimmer’s (1999) model is to promote self-directed physical activity pursuits for persons with disabilities with family and friends, thereby making health promotion for persons with disabilities a priority.

Peters (1996) presented a model of disablement that also expanded the medical view of disability. He described what he feels are the key components of the disablement process, including the structural and functional changes that come with impairment. He also suggests that socio-cultural processes are at play when impairment becomes labelled as a disability (see Figure 2). The term “disablement” describes how the consequences of trauma, disease, and disorders interact with the environment. Socio-cultural influences affect functioning of specific body systems fundamental to physical and cognitive actions (Verbrugge & Jette, 1994). Both the objective (disability observed) and subjective (disability experienced) characteristics of impairment and the impact of the biological manifestations of impairment on function, and the role that society can play in the production of disability are emphasized in Peters’ (1996a) model of disablement. Moreover, Peters’ model melds the World Health Organizations International Classification of Impairments, Disabilities, and Handicaps (ICIDH) of 1975 and the subsequent biosocial revisions of 1980 and 1993.

ICIDH defined impairment as any loss of psychological, physiological, or anatomical structure or function. The ICIDH further defines disability as a medically or psychologically diagnosable condition such as blindness, deafness, paraplegia, intellectual limitations or diabetes, which reduces functional ability and activity within the range considered normal for a human being. Finally, the ICIDH defined a handicap as an environmental and/or social barrier such as a lack of awareness that limits or prevents an individual with a disability from fully participating in those normal everyday activities and opportunities that we all expect and accept in life.

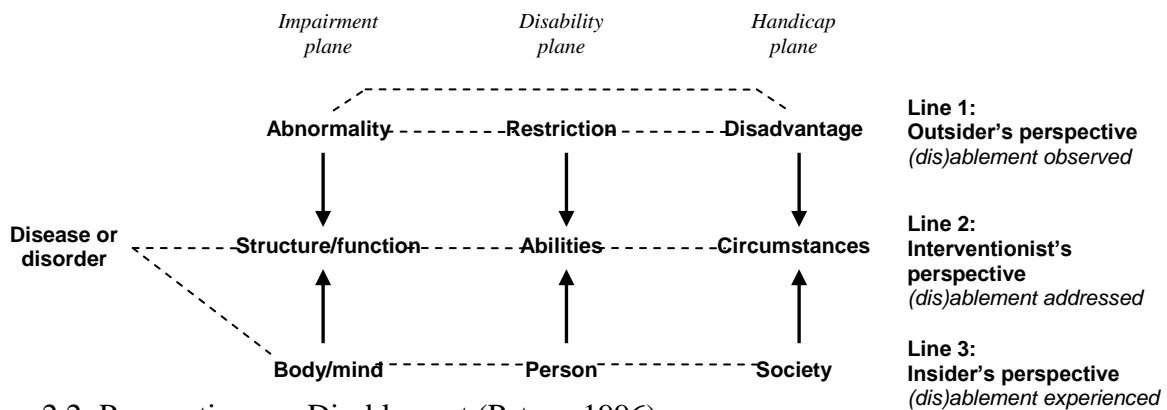


Figure 2.2: Perspectives on Disablement (Peters, 1996)

Although the term handicap is no longer in common usage and does not appear in the 2001 International Classification of Funding Disability and Health (ICF), the terms impairment and disability remain. The ICF describes changes in body function and structure, what a person with a health condition can do in a standard environment (their level of capacity), as well as what they actually do in their environment (their level of participation). In the ICF the term functioning refers to all body function, activities and participation, while disability is an umbrella term for impairments, activity limitations, and participation restrictions – thereby positioning function within the context of personal and environmental barriers and facilitators – or what is being termed a bio-psychosocial model (WHO, 2001).

Changes in the World Health Organization’s definition of impairment and the shift to a bio-psychosocial understanding of the disablement process, reflects the centrality of the person in our understanding of disability and disability service provision. This sentiment is underscored in Peters’ (1996a) model of disablement, which integrates disablement into: (a) three domains of disablement (i.e., body, person, and society), (b) three perspectives of disablement (i.e., outsider, interventionist, and insider) and (c) the interaction between these domains and perspectives.

The *body* refers to the structural and functional changes a person experiences as a result of impairment. The *person* refers to how an individual responds to this structural/functional change, his or her attitudes, sense of self and psychological mind-set. *Society* exemplifies the societal influences an individual with a disability faces and the characteristics of these influences (e.g., disadvantages or accommodations) (Peters, 1996).

Peters (1996) describes disablement through the eyes of an *outsider* - disablement observed, an *interventionist* - disablement addressed, and an *insider* - disablement experienced. The *outsider's* perspective of disablement as described by Peters (1996) is characterized by the objective description of impairment such as those found in textbooks, professional journals, and medical classification systems. Peters (1996) description of the *interventionist's* perspective of disablement is characterized by the concrete application of the outsider's knowledge to maximize the individual's abilities by increasing or maintaining function. Interventionists often work directly with individuals with disabilities (e.g., occupational or physical therapists on a rehabilitation unit). The *insider's* perspective of disablement refers to the subjective experiences of an individual with a disability and the relationship of these experiences with the domains of disablement (the body, the person, and society) (Peters, 1996).

The transition from rehabilitation to home and community is marked by the actions of insiders, interventionists, and outsiders. I was particularly interested in the interaction between the insider's perspective and the domains of disablement (body, person, and society) as the focus of my research was to both explore the meaning of the lived experience of young adults with spinal cord injuries and to give voice to people who have experienced the rehabilitation process.

2.3 Conceptual Framework

The transition from hospital to home and the community is a commonly stated outcome of rehabilitation (Carpenter et al., 2007; Gage, Cook & Fryday-Field, 1996; Kuczewski & Fielder, 2005). Post discharge planning and support is essential for the reduction of unplanned re-admissions and coordination of community services (Turner et al., 2008). For persons with acquired injuries resulting in functional impairment and disability, a key transition occurs at the time of discharge from the hospital. Hospital-based transition services typically serve two functions, (a) bridging the gap between in-patient rehabilitation and home and community and (b) facilitating greater independence (Turner et al., 2008; Hebert & Ashworth, 2008). It is a time of optimism (Olofsson, Andersson & Carlberg, 2005), but also uncertainty for the person and family members involved. People and families feel ill prepared and emotionally insecure about community living and once discharged feel isolated and experience difficulty identifying and accessing services (Cott, 2004; Cott, Wiles, & Devitt, 2007). We also know that coping strategies are moderated by self-perceptions of competence, personally held beliefs, and physical self-perceptions (Goodwin & Thurmeier, 2004; Sabiston et al., 2007; Wheeler et al., 1996).

Absent from transition models is education and encouragement to assist people with physical disabilities to manage their own health through physical activity when they return to the community (Rimmer, 2002). Although transition planning is deemed important, a gap in knowledge and the requirements for linking rehabilitation and community programs continues to exist as little is known about the experiences of those discharged from rehabilitation (i.e., insiders) and the extent to which the skills they acquired through rehabilitation are sustained upon return to the community (Turner et al., 2008).

Schlossberg's transition model (Schlossberg, 1981; 1991; Schlossberg, Waters, &

Goodman, 1995) provided a valuable heuristic framework for reflecting upon the meaning people with spinal cord injuries give to physical activity participation as they make the transition from the rehabilitation setting to the reality of returning to their homes and communities. The model describes four factors that influence the ability of a person to cope during transition: (a) situational variables (event trigger, timing, role change, duration, previous experiences, concurrent stress), (b) the self (individual readiness, personal and psychological resources), (c) support (types, function of supports) and (d) strategies (responses available, action taken, knowing when not to take action).

For the purposes of this study, I am interpreting ‘community’ to be where the participants were living prior to their spinal cord injuries, including the location where they spent time with family and friends, and where they were involved in school, work, and sport. I believed community to be integral to how the participants described their lives and who they were prior to and following their spinal cord injuries.

2.4 Purpose of the Study

My study explored the meaning people with spinal cord injuries gave to participation in physical activity as they made the transition from the protected environment of hospital rehabilitation to the reality of returning to their homes and communities.

3.0 METHODOLOGY

3.1 Research Design

To understand physical activity for people with spinal cord injuries as they move from in-hospital rehabilitation back into the community, it was important to understand their day-to-day experiences through their own words (insider's perspective) and not through the words of their physicians (outsider's perspective), their therapists (interventionist's perspective) or their families.

Utilizing a qualitative research design afforded the opportunity to understand how the participants constructed the meanings they gave to their lives following their spinal cord injuries (disability plane). A qualitative researcher attempts to understand the meaning of human experience by collecting and analyzing information that is provided by the participants (Peters, 1996b). Data commonly takes the form of audio taped stories, field notes, memos, or other collected artefacts (Creswell, 1998). Gathered stories are then analyzed, seeking the thematic structures that are common to the phenomenon of interest (Peters, 1996b, van Manen, 1997).

Phenomenological research is the study of lived experiences with the aim of describing and interpreting our everyday experiences (Creswell, 1998). My research approach was informed by the tradition of a phenomenological descriptive method (van Manen, 1997) which is well suited to disability studies as it allowed me to explore and describe the meaning of the participants' lived experiences of a shared phenomenon (Creswell, 1998; Giorgi, 1982; Paterson & Hughes, 1999; van Manen, 1997).

My initial thought was to conduct a phenomenologically informed case study, as I believed each participant would present a different story relative to her or his experiences, when moving from in-hospital rehabilitation into the community. When I speak of in-hospital

rehabilitation, I am referring to the time the participants spent on the rehabilitation ward as in-patients at the rehabilitation hospital. During the rehabilitation process, patients complete a rehabilitation program that focuses on learning how to live with a spinal cord injury. Therapists assist the participants by teaching them how to perform daily living activities such as dressing, grooming and transferring to and from their wheelchairs.

I expected each participant's story following a spinal cord injury to be different for a number of reasons, including past experiences, varying levels of injury, and different levels of family support while moving through rehabilitation. Each participant may bring unique backgrounds. For example, participants from rural areas, and urban areas, as well as participants who were raised in two-parent families, single parent families, and mixed families have varying life experiences moulding their biographies. The participants may also have experienced different causes of injury (e.g. falls or motor vehicle accidents). I expected different stories to emerge as the participants experienced different levels of support.

In other words, because I expected to hear different stories and experiences from each participant, I initially planned to present the information received in individual case studies. These thoughts were quickly dispelled as I came to hear each participant's compelling stories, and the remarkable similarity of their experiences. Therefore, because of the participants' common experiences, the data was analyzed and presented as themes common to all of the participants' experiences. As methods of qualitative research can emerge as researchers work to distance themselves from their own a priori constructs at the beginning of the research (Guba & Lincoln, 1982), it was decided that the thematic analysis would be completed across participants and the themes presented as their joint voices.

3.2 Sampling Strategy

A phenomenologically informed research design requires the selection of participants who have in-depth experiences with the phenomenon being studied (Creswell, 1998; Johnson, 1997). Moreover, qualitative research focuses on relatively small samples that are purposefully selected to permit in-depth understanding of a phenomenon and to maximize discovery of patterns that emerge from the particular context under study. Three to 10 participants that provide sufficiently thick, rich data for the researcher to reach data saturation are recommended (Creswell, 1998). Data saturation refers to the process of continually collecting data until the information begins to repeat itself (Meadows & Morse, 2001).

Creswell (1998) suggests that purposeful criterion-based selection strategies are ideal for phenomenologically informed studies. Purposeful selection strategies allow the researcher to purposefully select participants who will provide thick, information-rich data relevant to the phenomenon being explored (Patton, 2002). Criterion-based selection strategies also allow the researcher to establish predetermined criteria when selecting participants, thus providing the researcher with the ability to select participants who have the ability to answer research questions (Goetz & LeCompte, 1989). Participant inclusion criteria for my study included:

- Presence of a spinal cord injury
- Willing to share rehabilitation experiences
- Young adults between 13 – 29 years
- Time since injury 1 – 5 years
- Discharged from in-patient rehabilitation
- Participated in self-defined physical activity pursuits following rehabilitation

Participants were not included in my study if they had physical, cognitive, or mental health

concerns that would interfere with their ability to participate in self-reflective interviews.

As there is a low incidence of annual spinal cord injuries in Saskatchewan, and the timeframe to complete a Master's program is limited, my sample did not reflect specific demographic variables such as geographic location, level of spinal cord injury lesion, or sex. For this reason, my participants were both paraplegics and quadriplegics and were from rural and urban communities.

I chose to select participants who had been injured for a minimum of one year as my experience as a rehabilitation counselor suggested that there is an adjustment period that individuals go through before feeling comfortable enough with their spinal cord injury to share their personal experiences. In-hospital rehabilitation can be very intense and individuals in this situation may not be ready to discuss the rehabilitation process. I was seeking to understand the physical activity experiences of young people with spinal cord injuries between 13 – 29 years old, who have the highest incidence of spinal cord injury (Jackson, Dijkers, Devivo, & Poczatek, 2004), and from my experience as a rehabilitation professional are more likely to return to physically active lifestyles than older adults who are injured. Also, the funding received to conduct this research was provided by the Hospital for Sick Children's Foundation that supports research pertaining to children and youth health. Finally, being discharged from in-patient rehabilitation gave the participants an opportunity to reflect upon their experiences and provided time to experience physical activity in the community.

3.3 Participants

Participant recruitment was facilitated through the Saskatoon Health Region's therapeutic rehabilitation department at Saskatoon City Hospital, as well as with the support of Dr. Griebel, a

neurosurgeon with the Saskatoon Health Region. In addition, I volunteered as a community physical activity liaison with the Therapeutic Recreation Department at Saskatoon City Hospital and built an excellent rapport with the therapy department's staff who were very supportive and interested in my proposed research.

With the hospital support, my volunteer work, as well as through my own personal contacts, 4 of 6 individuals from the Saskatoon area who had sustained spinal cord injuries and met the eligibility criteria volunteered to learn more about the study. Once given the contact information of the potential participants from my hospital contacts, or through my personal knowledge of the individuals, I explained the nature of my study to them in person or on the phone. Following initial contact, I provided each individual with a package of information, including a letter explaining my study and a copy of the consent form. All 4 individuals agreed to participate. Interestingly, all participants who met the criteria at the time of my study were female. The reported spinal cord sex distribution of men to women is 3.8 to 1 (Wyndaele & Wyndaele, 2006),

The age of the participants with spinal cord injuries was between 15 - 24 years of age, which also has been documented as the age range of the highest incidence of spinal cord injury (Jackson, Dijkers, Devivo, & Poczatek, 2004). All participants had been injured for 2 – 5 years with the exception of one participant who was injured 20 years at the time of the study. This person was included in the study even though she did not meet the eligibility requirement of time since injury because of the interest and insight that she expressed when she learned I was conducting this study. She was initially introduced to physical activity and sport for people with spinal cord injuries as a teenager coming from a rural area to an urban centre. Her experiences with physical activity and sport were much the same as the other participants' initial involvement

in physical activity and sport following their rehabilitation discharge. This participant had also gone on to contribute a great deal back to the wheelchair sport community as a mentor, coach and leader. I felt she had a great deal to contribute to the study. With the recognition that recall may be a challenge and could potentially impact the depth of the information gained, she was invited to join the study. Her recall information was used from the point of her teenage years and initial wheelchair sport involvement forward. My initial concerns that the participants would not be able to recall their rehabilitation experiences in depth with the passage of time were allayed as I began to hear the stories of the participants. I quickly realized how poignant those memories were and how effective interview triggers such as the smells, sounds, and sights of rehabilitation brought memories to light. For this reason, I now believe I could have chosen individuals who had been injured for more than 5 years.

At the time of the study, all 4 participants were living in an urban setting. One participant was living on their own and working and the remaining 3 were living at home with their parents, either attending high school, a post secondary institution, or volunteering in the community.

In my experience, people with spinal cord injuries refer to the location of their spinal cord injury as the “level of injury”, meaning where, on the individual person, the spinal cord sustained damage (see Figure 3.1). The level of spinal cord injury is indicated by the name and location of the vertebrae where the damage occurred. The vertebrae are the bones in the human back, and the spinal cord is the bundle of nerves that forms a cord that extends down the centre of the vertebrae from the brain stem to the tailbone (Canadian Paraplegic Association, 2006). The actual spinal cord must be damaged for an individual to lose function and mobility.

In the neck, for example, humans have 8 cervical vertebrae. If an individual sustains a spinal cord injury between the 5th and 6th vertebrae, their level of injury is referred to as C5-6

spinal cord injury. There are 12 vertebrae in a human back called thoracic vertebrae, followed by 5 lumbar vertebrae in the lower back and 5 sacral vertebrae in the tail bone area. A spinal cord injury to the upper portion of the back, between the shoulder blades for example, would be referred to as T4 spinal cord injury. This is because the injury occurred at the fourth thoracic vertebrae. A lower back spinal cord injury at the second lumbar vertebrae would be referred to as an L2 spinal cord injury.

The level of injury also determines the level of function. An individual will have less function and movement the higher up the spinal cord the injury occurs. A spinal cord injury to the neck (cervical vertebrae) will result in quadriplegia, as all four limbs of the individual with the injury will be affected. A spinal cord injury to the back (thoracic or lumbar vertebrae) will result in paraplegia, as the individual's lower two limbs that are affected.

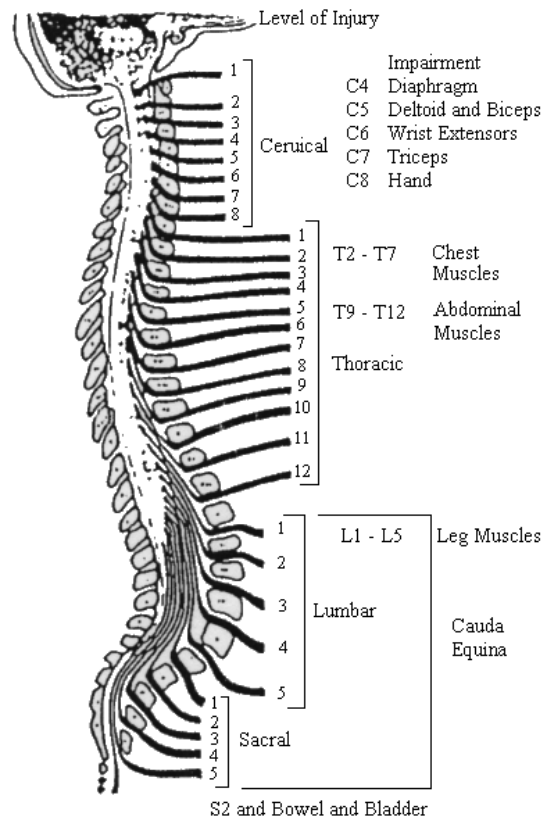


Figure 3.1. Level of Injury (Nova Scotia, Canadian Paraplegic Association, 2006)

The level of spinal cord injury of the participants varied from mid-level quadriplegia to low-level paraplegia. All participants used wheelchairs for mobility. The participants who had sustained cervical spinal cord injuries (neck injuries) were mid-level quadriplegics and had function from mid chest up, meaning they had the use of their arms and wrists but little or no use of their fingers. They also had poor balance due to a lack of functional trunk muscles or muscles below the middle of their chests. The participants with thoracic spinal cord injuries (back injuries) were high to low level paraplegics. The high level paraplegics sustained spinal cord injuries to the upper portion of their spinal cord between their shoulder blades. In summary, two of the participants were quadriplegics while the other three were paraplegics. The period of time the participants spent in hospital rehabilitation ranged from 3 to 12 months. The participants' ages, time since injury, and involvement in disability sport are summarized in Table 3.1.

Table 3.1 Description of Participants

Name	Age (Yrs)	Age at SCI (Yrs)	Yrs Since SCI	Level of SCI	Disability Sports Involvement	Years of Involvement
Gabriel	24	4	20	T2-4	Sit Skiing, Athletics, Fitness, & Basketball	9
Edie	18	16	2	T12-L1	W/C Athletics, Fitness, Water skiing,	1
Tatiana	21	16	5	C6-7	W/C Athletics, Rugby, Swimming, Water skiing, Basketball, Wheeling, Fitness	4
Bree	23	21	2	C6-7	W/C Rugby, Fitness, Basketball	1

W/C = Wheelchair

The level of support from family and friends for each participant while they were in rehabilitation varied. Participants from the urban centres indicated that they had family and friends with them continuously, while participants from the rural areas indicated that their level of family and friend support was high but reflected the distances that friends and family needed to travel.

Participants identified themselves as being physically active prior to sustaining their spinal cord injuries and continued to be physically active following their injuries. The activities identified included (a) hand cycling, weight lifting, casual wheeling (going for walks), and water skiing, (b) individual sports such as athletics and alpine skiing, and (c) team sports such as Wheelchair Rugby and Wheelchair Basketball.

3.4 Data Collection

Studies that are informed by a phenomenological research approach gather information using various methods, including observations and field note taking, in-depth one-on-one interviews, focus group interviews, and/or artefact collection (Creswell, 1998; Morse, 1994). The data collection methods used for my research included demographic background information, in-depth one-on-one semi-structured interviews, a focus group interview, artefact collection, and field notes (Creswell, 1998). Observation is a qualitative research method which provides an opportunity for the research to observe what they are researching (Creswell, 1998). As my data collection consisted of reflected interviews requiring the participants to recall events of the past, I did not incorporate the qualitative research method of observation.

The participants were individually interviewed three times over the course of the study,

followed by a focus group interview. The individual interviews were retrospective in nature and focused on the following three distinct time periods, (a) as patients on the rehabilitation ward of the hospital following their injuries, (b) 6 months to 1 year following the participants' discharge from in-hospital rehabilitation and (c) 18 months to 2 years following the participants discharge from in-hospital rehabilitation. These time periods were selected to capture the transition from therapy within the rehabilitation hospital to community-based health promotion. The first two years following a spinal cord injury involve huge physical, social and emotional changes in an individuals' life, including the opportunities to participate in physical activity (Vissers et al., 2008). For this reasons, I chose to further explore physical activity and spinal cord injury during the first two years following injury. These time periods also align with Rimmer's model (1999) of health promotion. Table 3.2 provides a summary of the data collection schedule.

Table 3.2 Data Collection

	In-hospital Rehabilitation	6 -12 Months Post Discharge	12 – 24 Months Post Discharge	Future Aspirations
Data Collection	One-on-one interviews	One-on-one interviews	One-on-one interviews	Focus group interview (all participants)
Methods	Artefact collection	Artefact collection	Artefact collection	

All interviews were audio taped and transcribed verbatim. I also kept field notes of individual interviews and the focus group interviews, which assisted data analysis by allowing me to conceptually return to the interview settings. All audio and documented records are kept confidential and stored in a secure locked office. Pseudonyms were used to protect the identity of the participants. A copy of the Ethics Certification can be found in Appendix A.

The data collection process began with the gathering of background demographic information on the participants (see Appendix C). Using an information form facilitated the efficient collection of personal information (e.g., age, address, and employment status), thereby providing maximal interview time to explore the research question with the participants.

3.4.1 Individual Interviews

I utilized in-depth, semi-structured, conversational interviews to stimulate focused, two-way communication (See Appendix D and E). Although the interviews were semi-structured, they were conducted as a friendly conversation (Spradley, 1979; van Manen, 1997). I allowed the participants to speak freely about their rehabilitation experience, interjecting only to keep the conversation focused on the specific timeframe being discussed. This was necessary, as the interviews were retrospective in nature and the participants easily drifted between their time in rehabilitation and their experiences at the time of the interview. For example, one participant had been injured for 4 years and was still exploring new physical activity opportunities. She spoke freely of her physical activity experiences in rehabilitation and, just as easily, spoke of her recent experiences at the time of the interview, as those experiences were similar in nature.

The interview guide was pilot tested. During the pilot interview, it became apparent that the participant, who had sustained a spinal cord injury 4 years prior, was able to reflect retrospectively on her time in rehabilitation. She was able to recall and provide in-depth accounts of her experiences as an in-hospital patient on the rehabilitation ward. I encouraged the pilot interview participant and the subsequent participants to think about the smells, the physical setting, and the clothing they wore during their time in rehabilitation to provide useful sensory cues for recalling memories of the time period we were discussing. The participants indicated

that they were able to bring themselves back to the timeframe under discussion.

Each interview was one to two hours in length and took place in the participant's home, my home, or the Saskatoon Fieldhouse. All the participants were able to recall, retrospectively, the first 2 time periods. The first interviews focused on the participants' experiences with physical activity while on the rehabilitation unit as in-patients. When interviewing the participants, I was looking to see what they experienced as in-patients in a typical day. The experiences the participants shared reflected a typical day of activities including strengthening programs with weights in physical therapy, wheelchair skill exercises in occupational therapy, and the community outings with a recreational therapist.

The second interview focused on the participants' transition experiences from the rehabilitation setting to their homes and communities six months to one year following their discharge from the rehabilitation unit. From my own personal experience, and the experience I have had working as a counselor, I believe this is a very important time for people with spinal cord injuries. In my experience as an insider, six months to one year following a spinal cord injury appears to be a period of adjustment, when many individuals learn a great deal about the impact of their injuries on their lifestyles as they return to their homes and communities.

Typically, the decision to be discharged is made by a team of medical professionals. This team includes physicians, therapists, and care staff. After being discharged from in-hospital rehabilitation, individuals often continue a rehabilitation program as outpatients. Outpatient rehabilitation means the individual is living in the community but returns to the rehabilitation hospital for therapy on a regular scheduled basis until the team has decided that this individual no longer requires out-patient rehabilitation. The participants discussed not only their physical activity experiences as rehabilitation outpatients but also their experiences in the community

upon returning home from the hospital.

The third interview focused on the timeframe of 18 to 24 months following the participants' discharge from the rehabilitation unit. Two of the participants had been out of the hospital for more than 24 months meaning that the final interview with these participants was retrospective in nature, as were their first 2 interviews. The other three participants had been injured for less than 24 months, making this final interview a real time interview, meaning they were living in the same time period that we were discussing in the interview.

The use of sensory cues worked well as a stimulus for discussions because the in-hospital rehabilitation setting had very distinct sensory markers, a setting not easily forgotten. As I was using these cues with the participants, I found myself drifting back to my own rehabilitation experience some twenty years ago. This was an unexpected feeling and one that helped me to relate to the participants. Having gone through a similar experience myself, I could understand the participants' perspective.

In addition, I worked as a community volunteer with the recreation therapist on the rehabilitation ward for a number of years and had the opportunity to meet 4 of the five participants prior to the study while they were going through in-hospital rehabilitation. When the participants reflected on their time in rehabilitation, I was able to also reflect to the time when I first met them, remembering the activities and discussions we had first hand. This was an awesome experience because I was able to listen to the participants' side of the story and learn from them what their rehabilitation experience was really like. These interviews also gave me an opportunity to relate very closely to the participants, thus increasing their comfort level in sharing their stories with me and allowing them to open up. I felt that my credibility as an insider (Peters, 1996) created an authentic and respectful environment for the sharing of very personal

periods of the participants' lives.

Another interesting component, which I found quite enlightening, was that the participants' stories and experiences were not unlike my own experience in rehabilitation in 1984. This took me back and gave me an opportunity to reflect on my own experience with rehabilitation. I believe my experience allowed me to easily relate to the participants' experiences on a personal level, thus providing me with credibility as a researcher and the opportunity to build rapport with the participants. I also believe this enhanced my ability to interpret the findings and "brought home," Peters' (1996a; 1996b) conceptual framework of an insider's point of view, as I am myself a person who has experienced and lives with a spinal cord injury.

However, as someone with a spinal cord injury myself who had experienced rehabilitation, community transition and physical activity, I reminded myself that I was there to listen and have the participants describe their experiences in as much detail as possible. I was continually vigilant in my analysis, reflecting upon the presence of my own voice. I also consulted with my supervisor on a regular basis as I analyzed and interpreted my findings.

3.4.2 Artefact Collection

Artefacts can assist the researcher understand the meaning of, and give shape to, the lived experiences of their participants (Creswell, 1998). An artefact such as a photograph, a painting or a special gift may represent a significant moment from our past that may assist us to reflect on, clarify and provide detail of the experiences to which we give memory – or lived experiences (van Manen, 1997). The artefacts also provided stimulus for discussion and a means for the participants to return to specific time periods of interest.

I requested artefacts that represented a memory of physical activity during the retrospective timeframes. For example, the first artefact was to represent an experience of physical activity during in-hospital rehabilitation, whereas the third artefact was to represent an experience of physical activity within the community. The artefact could be a personal possession such as a photograph, a written document, or a piece of rehabilitation equipment. This provided an opportunity for the participants to share a tangible piece of memorabilia that stimulated their memory as they reflected on their past experiences.

The artefacts I received from participants were significant to them and assisted in the recollection of the participants' experiences during the retrospective interviews. Some of the artefacts I received included a picture of a back brace, which the participant wore for a number of weeks following back spinal surgery; and a journal, which friends and family began writing in daily while this participant was on the intensive care unit. Her family and friends continued with their journal entries while she continued her in-hospital rehabilitation. Many of the photographs I also received are depicted in the Results Chapter.

The photographs provided by the participants would allow the participants to be identified. For this reason, I have removed the faces from a number of the photographs to protect the identity of the participants. The participants' photographs without the faces removed have been used with full permission from the participants.

3.4.3 Focus Group Interviews

A focus group interview is a discussion with a group of people that addresses a specific topic relevant to the group (Berg, 2004). A typical focus group interview is guided by a moderator who draws out information from the participants relevant to the topic, and provides in

turn opportunities for all members of the group to speak freely (Kruger, 1994). The purpose of the focus group was to allow participants to guide the discussion in a safe, confidential, non-intrusive environment (Krueger, 1994), thus providing an opportunity for the participants to describe their experiences with physical activity since their spinal cord injury. The focus group was also used as a debriefing tool for the research process, a way in which to exit the research relationship with the participants, and finally as a tool for member checking the preliminary analysis results of the data collected (Patton, 2002). Finally, I wanted to bring closure to the study for the participants.

Initially, I had intended to conduct one focus group with all participants, but found it difficult to find a time when all 4 participants could meet. For this reason, two focus groups were held – both with two participants. I moderated both focus groups, each of which lasted approximately one hour.

During the focus group, the participants discussed their present physical activity experiences and aspirations as well their views on potential changes that would improve the transition process from rehabilitation to the community. The topics discussed included, the potential for rehabilitation specialists (physical therapists, occupational therapists, recreational therapists) to improve the transition process from rehabilitation to the community and the potential for rehabilitation departments and community organizations to work together to provide enhanced services for people with spinal cord injuries in the community.

3.5 Data Analysis

Thematic analysis is “a free act of ‘seeing’ meaning” (van Manen, 1997, p. 79). To analyze the meaning, structure, and essence of the participants’ experiences, a thematic line-by-

line analysis of the interview data was completed (van Manen, 1997). Thematic analysis identifies common structures of the particular experiences under study and is the primary mechanism by which understanding is achieved (Morse, 1994). It entailed reading the interview transcripts and field notes numerous times. Particularly, revealing phrases were highlighted and coded with meaningful labels. Codes that are conceptually similar were gathered together into thematic statements, giving fundamental meaning to the experiences (Patton, 2002).

The steps that were followed included (1) *horizontalization* - dividing data into common statements and coding them with meaningful labels) (2) grouping these codes into a *cluster of meanings* (phenomenological thematic concepts) and (3) compiling clusters in a *textural and structural description* (describing what was experienced and how it was experienced) (Creswell, 1998).

In the process of horizontalization, the transcribed interviews were read and re-read to obtain a broad understanding of content, looking for common ideas that could be grouped into meaningful clusters (Patton, 2002). The next stage was to tie the clusters of information gathered together through the development of common themes. I took these ideas and clusters of information back to the participants for confirmation that the themes I had drawn out were an appropriate and accurate interpretation of the participants' experiences. The themes were general descriptions of the participants experiences as they pertained to my research question, otherwise referred to as textural descriptions (invariant themes) and structural descriptions (imaginative variation) (Patton, 2002). The invariant themes were the main themes found throughout my data and were further examined and described through sub themes. The themes found were common links that were reflected in all of the participants' interviews, essentially telling the story of the participants experience with rehabilitation and the transition to physical activity in the

community. Through the process of analysis, I was able to draw out the common essences or meaning of the lived experiences of the participants (Creswell, 1998).

I asked the participants to verbally describe the significance of the artefacts they provided and how these artefacts related to their experiences. As the participants began describing their artefacts, I realised how significant the artefacts were in taking themselves back to their rehabilitation experiences.

The artefact descriptions were audio-taped in the same fashion as the interviews. The transcribed artefact descriptions became part of the research data and were thematically analyzed along with the interview data.

3.6 Trustworthiness

Trustworthiness refers to the quality of an investigation and its findings that make it noteworthy to its audiences (Schwandt, 1997). Qualitative researchers establish trustworthiness of research findings through various strategies including credibility, transferability, dependability and confirmability (Berg, 2004; Janesick, 1994; Meadows & Morse, 2001). The names given to the strategies have varied over time (e.g., plausibility, authenticity), but the intent of the strategies remains consistent (Meadows & Morse, 2001). The trustworthiness strategies undertaken are summarized in Table 3.3.

Table 3.3 Summary of Trustworthiness Strategies

Trustworthiness Criteria	Application to Study
Credibility (Verification)	<p>Researcher credibility</p> <p>Research question within literature</p> <p>Purposeful sampling</p> <p>Data saturation</p>
Transferability	<p>Rich description</p> <p>Detailed participant description</p>
Dependability (Validation)	<p>Member checks</p> <p>Audit trail</p>
Confirmability (Neutrality)	<p>Data triangulation</p> <p>Investigator triangulation</p>

3.6.1 Credibility

Credibility or “verification” refers to the techniques and methods used to substantiate the accuracy of research findings (Meadows & Morse, 2001). Credibility also ensures that techniques and methods used are effective in answering the research question (Jansick, 1995). As an integral component of my research design, I implemented credibility in the following ways:

- My research question was situated within the current literature pertaining to the

process of disablement, rehabilitation, and physical activity following a spinal cord injury.

- Purposeful sampling was used to select my participants. With the help of the rehabilitation hospital, I carefully selected participants who met the criteria I developed for participant selection and were able to answer my research question.
- Data saturation is the process of continual collection of data from participants until no new information is provided (Creswell, 1998). I heard repetition in the experiences described across participants.
- Researcher Credibility - the researcher has lived with a spinal cord injury for over 20 years and counseled people with spinal cord injuries. I identify myself as an *insider* with an understanding of physical activity and spinal cord injury (Peters, 1996). As my data collection began to unfold, I found myself remembering not only my own experiences in rehabilitation, but also my experiences as a counsellor who had worked with some of the participants during their rehabilitation process. In recognizing these memories and experiences as my own, I documented them in a personal journal and discussed them with my supervisor providing a context in which I reflected upon during the analysis of the findings.

3.6.2 Transferability

Naturalistic transferability is the ability to take the findings from a particular qualitative study and apply it to a similar group or context (Lincoln & Guba, 1985). The use of thick, rich descriptive data may allow a reader to transfer the findings of a qualitative research study across groups or settings.

- Rich descriptions - The data gathered from individual and focus group interviews provided my research study with a vast amount of thick, rich data (Patton, 2002).
- Participant information - I described the participants in detail, providing background information, facilitating the meaningfulness of the findings.

3.6.3 Dependability

Dependability or “validation” is the ability to collect a true and accurate account of the participants lived experiences with little reason to doubt the truth of the findings (Meadows & Morse, 2001). Dependability was established through:

- Member checking: A process of continually taking data interpretations back to participants and checking with them to ensure that I, as the researcher, correctly interpreted the meanings within the data they provided (Creswell, 1998; Guba & Lincoln, 1982). There was an extended period of time that I was able to interact with the participants during this research. Following the interviews, each participant was provided with a copy of her transcript for verification. At this point, there were a few participants who added content to their transcripts for clarification. I then went back to the participants to confirm the accuracy of the thematic analysis and theme development. Finally, I returned the transcripts to the participants and discussed the results portion of my research study. The participants selected photographs from their personal collections, matching them with the appropriate quotations from their transcripts. In other words, the stories of the participants were told and confirmed by the participants themselves, in turn lending dependability of my research. During this member checking process, I communicated with the participants over the telephone,

through electronic mail, and in person.

- I also created an audit trail during my research study. An audit trail is the actual documentation (i.e., interview transcriptions, artefact collection, researcher's journal, notes, and other documents) collected during a study. It creates a trail and forms a running account of the research process (Guba, 1981; Meadows & Morse, 2001). By examining the process of the inquiry and examining the product (data, findings, interpretations, and recommendations), an auditor can establish both dependability and confirmability in the inquiry (Lincoln & Guba, 1985). I had regular meetings with my supervisor and fellow students in person and through electronic mail over the course of the study. These meetings and this sharing of progress was a form of peer debriefing that also allowed my fellow students to provide me with feedback on the progress of my study. Meeting regularly with my supervisor was another form of peer debriefing that provided me with feedback and direction. The use of journal entries to record analytical notes of my progress and decision-making was also useful during this research period. Furthermore, I documented all communication between myself and my participants, fellow students and supervisor over electronic mail. The combination of these various forms of documentation increases dependability of my study.

3.6.4 Confirmability

Confirmability refers to extent to which the information collected is an accurate representation of the participants' views and experiences and not researcher imposed biases (Berg, 2004; Guba & Lincoln, 1982; Schwandt, 2001). Confirmability was established through

the use of three data collection methods:

- Data Triangulation: The collection of data using multiple methods (Jansick, 1994).
For my study, I collected data using audio taped individual interviews, audio taped focus group interviews, artefact collection, and personal documentation in the form of journal entries, electronic mail, and the recording of meeting minutes during committee meetings with my supervisor and committee members.
- The process of investigator triangulation uses a team approach. For this research study it included the research supervisor, research committee members, fellow graduate students, participants, and myself as the primary researcher (Jansick, 1994).

4.0 RESULTS

Three themes became apparent from the thematic analysis (van Manen, 1996) of my research data. The themes reflected the three primary time periods for the study (i.e., in-hospital, 6 – 12 months post discharge and 12 – 24 months post discharge) and were (a) as my body heals – the participants’ journey through in-hospital rehabilitation, (b) learning to be me – the participants transition home, and (c) getting back to life – rebuilding physically active lives in the community. Through my data analysis, sub-themes emerged within each of the primary themes. These sub-themes provided further clarification and explanation of the participants’ experiences (see Table 4.1). Each of the themes with their respective subthemes will be presented and supported with the voices of the participants. You will notice throughout that although all voices are present in the results that the participant voices and level of valuable contribution are not equitable. As a new researcher I quickly realised that varying participant personalities and experiences meant varying levels of quality contributions by each individual participant. This is not to suggest that some voices were more important than others, but that the participants shared aspects of themselves and their stories of which they were most comfortable.

Table 4.1 Summary of the Thematic Analysis

THEME	SUB-THEMES
As my body heals	Everything is a challenge They were always there for me
Learning to be me	I need to do this on my own Too much help
Getting back to life	Validation through physical activity Learning from others

As the themes and sub-themes provide clarification of the participants' rehabilitation experiences and initial community experiences following their spinal cord injuries, it is important to acknowledge what physical activity meant to the participants as their bodies healed following their injuries. The participants' initial rehabilitation programs consisted of learning how their bodies functioned and how to move their bodies, which eventually lead to rehabilitation strengthening programs. Regaining physical strength through healing, and rehabilitation strengthening programs was a slow and physically draining process that was defined by the participants as physical activity. Rehabilitation strengthening programs eventually allowed the participants to transition to physically active lifestyles including recreational activities, community sport involvement and competitive sport.

4.1 As My Body Heals

As My Body Heals emerged as the participants shared their in-hospital rehabilitation experiences following their spinal cord injuries. Through their stories, it became clear that the injuries the participants sustained resulted in distinct and observable loss in the structure and function of their bodies, or what Peters (1998) refers to as impairment. Furthermore, because the impairment restricted the ability to perform desired activities, the participants also faced the reality of disability (WHO, 2001). The interaction of the objective features of disability (e.g., impairment and activity restriction) (Peter, 1998) with the psychological and emotional realities of learning how to move their bodies given their level of impairment caused by their spinal cord injuries, were evident in their stories. Simple everyday activities such as getting out of bed and dressing, which one takes for granted, suddenly became very challenging and difficult activities.

In-hospital rehabilitation was described by the participants as initially being a time when they felt physically exhausted and emotionally overwhelmed. This initial phase of rehabilitation, focused on the body/mind interaction required to come to a new sense of self as an individual living with a spinal cord injury. Rehabilitation was later described as an educational experience as the participants began to learn new physical and technical skills during their physical therapy, occupational therapy and recreational therapy. As Rimmer (1999) depicted in his health promotion model, physical therapy played a large role in the participants' rehabilitation experiences.

In addition, the participants spoke of how friends, family, and hospital staff mediated their early experiences of disability beyond managing the structural and functional changes of their bodies. The sub themes, everything is a challenge and they were always there for me further described the participants' experiences during their in-hospital rehabilitation.

4.1.1 Everything is a Challenge

In-hospital rehabilitation was described by the participants as a time of healing both physically and psychologically. Physically, the participants spoke of how their bodies needed time to heal from the multiple injuries they sustained as a result of what is commonly referred to in the hospital as catastrophic incidents. Besides damaging their spinal cords, the participants described the other injuries they sustained including broken arms, cracked ribs and various bumps and bruises. Allowing their bodies to physically heal was a major part of each participant's initial hospital stay in the intensive care unit (ICU), move to the neurological ward, and finally the rehabilitation ward.

Rehabilitation was not initiated until the participants' injuries and health status became stable. Bree experienced a long recovery period on the neurological ward. She endured pneumonia twice, contributing to her extended stay on the neurological ward, delaying the transition to active rehabilitation. Bree recalled, "... because I was...so critical...I moved up to the neurological ward from ICU and then went back down to ICU. I ... never really saw any rehab for over three months."

Feeling exhausted and sleeping for many hours at a time was how the participants described their early days in the hospital. Edie recalled: "... you do most of your healing when you're asleep and I did a lot of damage, so my body just wanted to sleep all the time." Tatiana shared how she spent several weeks on the neurological ward recovering from her neck surgery and waiting for her body to heal before she was transferred to the rehabilitation ward (see Figure 4.1).

After the participants were transferred to the rehabilitation ward, they described their in-hospital stay as a time to rebuild their physical strength and learn how to function with a spinal

cord injury. Initially, Tatiana was taken aback with her first experiences in rehabilitation:

Oh my goodness, it was just overwhelming, I'm never going to make it here! ... the whole thing [rehabilitation] was just so big ... emotional, the littlest thing excited you so much. The first day I held my toothbrush with a cuff and brushed my own teeth was amazing. I kept this book and I still have it and we wrote down [things] like "today I held a toothbrush and washed my face" and then when I first held a pen and wrote something, that was pretty big.

The participants all stated that their rehabilitation felt like a building block for their transition home and the next leg in their journey as individuals living with spinal cord injuries.



Figure 4.1 Tatiana with her halo traction weeks after her surgery

Physical therapy was described by the participants as a time to rebuild their strength and

physical endurance by lifting weights and using the hand ergometer (arm crank machine). Bree described physical therapy as a place where she “worked on movements and transfers.” The participants were taught how to use the function they had to the best of their ability, and experiment with their new “paralysed” bodies. They referred to physical therapy as a place to begin moving their broken bodies and rebuild their physical strength.

Moving their bodies included activities such as learning how to roll over, transfer into and out of their wheelchairs and lift their paralyzed legs into bed. The participants described learning how to sit-up from the lying position without assistance, rolling themselves over by swinging their arms back and forth and learning how to slide their legs off the end of the mat and onto their wheelchairs using only their limited arm strength. These were difficult tasks, which Tatiana found exhausting, “[Rehabilitation] was exhausting. They start you off pretty slow and [I experienced] lots of dizzy spells. It took me a long time to sit up.”

Tatiana and Bree, both quadriplegics, described themselves as having no physical function below mid chest level, and their upper body movement, including arm and hand function was quite limited. Even the smallest tasks such as moving their bodies from the bed to their wheelchairs (transferring) required a huge amount of effort, strength and skill. Strengthening themselves to master these tasks was essential. Weight training therefore became a large part of the participants’ physical therapy programs and integral to readiness for hospital discharge. Each small success was reason for celebration even though the process was not always pleasant. Tatiana recalled:

Weights ... focused on getting me stronger ... if [I] moved up to one pound instead of zero that was ... the biggest day in the world! I did the arm bike, and the wheelchair treadmill and I hated them but I knew it was good for me.

All of the participants' stated how their primary rehabilitation goal was to live independently. Edie, a paraplegic, had the goal of returning home and continuing her life. She wanted to dress herself, continue school with her friends, and get her driver's license. She stated, "I'm a teenager ... and becoming independent ... is very important."

As Edie reflected on her goal of completing rehabilitation and returning home she recalled those first physical therapy sessions. "I was feeling weak ... you're lifting weights, you're doing like 5 pounds and you're just like this isn't what I could do before."

Strength training using weights and pulley machines as well as aerobic endurance building using the arm ergometer and wheelchair treadmill was significant components of the participants' physical therapy rehabilitation programs. The photographs in Figures 4.2, 4.3, and 4.4 illustrate the use of the equipment. Tatiana, with assistance from her therapists and her uncle increased her muscular strength and endurance and aerobic capacity. Tatiana began her exercise therapy when her post surgery halo brace was still in place. The brace is used to prevent the neck and head from moving and keeps the neck in the correct position as the injured spinal column and ligaments heal.



Figure 4.2 Tatiana lifting weights during physical therapy with her uncle



Figure 4.3 Tatiana using the arm ergometer in physical therapy



Figure 4.4 Tatiana on the wheelchair treadmill

Complementing physical therapy, occupational therapy was described by the participants as focusing on activities of daily living such as dressing, grooming, preparing meals, and using

adaptive aides to increase independence in home environments. One experience Bree shared related to her ability to feed herself. Prior to her injury this was a task she did not have to consciously consider. Bree worked with her occupational therapist and utilized hand splints to manipulate utensils, pencils, a toothbrush, a hairbrush and every other instrument one might use in their daily lives. Previously simple tasks such as holding a fork, placing food on the fork, and lifting it to her mouth became huge physical challenges for someone with little hand or arm function. Bree said, “Everything seemed so much more physically challenging than it has ever been. It was so hard just to do the smallest thing, like to just feed myself.”

Like Bree, Tatiana commented on very similar challenges that she worked on and strove to overcome while in rehabilitation. Tatiana provided a photograph of herself learning how to cook with the assistance of her occupational therapist in the Activities of Daily Living (ADL) suite. The ADL suite is a wheelchair accessible mock apartment used in rehabilitation to teach people with mobility impairments how to function independently in a home environment. Using the ADL suite, participants indicated that they began to prepare for their return home by working on tasks such as meal preparation. Below (see Figure 4.5) Tatiana illustrates using a splint to hold a knife to cut pizza.



Figure 4.5 Tatiana using a knife in a splint to cut pizza

The participants indicated that they were introduced to therapeutic recreation a few weeks into being on the rehabilitation ward – as they began to feel stronger and more independent. Therapeutic recreation was described by the participants as an introduction to physically active lifestyle choices that could be pursued in the community such as swimming (see Figure 4.6). The rehabilitation ward had a swimming pool on-site, providing the participants with a supervised physical activity and also a form of physical therapy. Tatiana loved swimming prior to her spinal cord injury and enjoyed opportunity to swim as part of her time in rehabilitation. She described swimming as a great physical workout, which helped strengthen her body while she was in rehabilitation.



Figure 4.6 Tatiana in the pool with her physical therapists

The participants described rehabilitation as a time of frustration and celebration melded together. They talked about how they often felt frustrated when the smallest, and what were previously simple tasks, became huge mountains to climb. A task such as pulling on a pair of socks with limited hand function was further complicated by severe dizziness from reaching for ones feet.

As illustrated above through the quotations and photographs, the participants had many stories about their experiences in rehabilitation following their spinal cord injuries. Rebuilding, relearning and coping as someone who had just experienced the life changing trauma of a spinal cord injury were common threads in the participants' stories. The participants knew they had to work on physically rebuilding and strengthening their bodies to function independently as someone with a spinal cord injury. "Everything was a challenge" is a reflection of the participants' stories and experiences in rehabilitation following their spinal cord injuries. They did not undergo rehabilitation alone, however.

4.1.2 They Were Always There For Me

All the participants spoke about the emotional and motivational support they received from family and friends while they were in hospital and completing their rehabilitation. They believed this external support was an important and significant component of their rehabilitation. Bree appreciated the support from her friends and family, “[The support I had] definitely helped, especially at the start when you just don’t know what the future holds.” Bree’s sisters, as well as her mother and other close relatives and friends wrote in a journal for Bree documenting her progress while she was in the hospital. Bree identified this journal as an important artefact which told the story of her time on the intensive care unit right through to the rehabilitation ward following her spinal cord injury. Although Bree had not felt comfortable reading through the whole journal at the time of our discussion, she shared a few of the entries with me, which included stories from many close friends and family members. The early journal entries were written to Bree while she was unable to speak, and included stories of inspiration, motivation and personal progress from those around her. Close family members who spent countless days by Bree’s bedside while she was in ICU told heartfelt stories of how Bree was progressing day by day. These stories told of the good days and the bad days as well as what treatments she had. These stories provided a context from which Bree was able to share the importance of friends and family as she moved from her very ill days in intensive care, to the neurological ward, and finally the rehabilitation setting.

Edie also told of how significant her family and friends were during her time in rehabilitation. Maintaining contact with friends was reassuring during a time when the participants feared they may lose contact with them.

Eddie went on to say:

There were three of my friends who were there almost every day when I was on bed rest. Whether it was my parents or a friend, there was usually always somebody in the room. It was really nice to have that support and know that everyone was still there for me and that everyone still wanted to be my friend.

The support the participants had from their family, friends and peers is also demonstrated by the actions of these individuals. Elaborately decorating their hospital rooms was very significant to the participants and their friends. They spoke of how the flowers, cards, stuffed animals and glow in the dark stars provided encouragement and emotional comfort during the long days, weeks and months in rehabilitation. Tatiana's described how her friends supported her by decorating her hospital room with inspirational posters and personal fun decorations (see Figure 4.7). Figures 4.7 and 4.8 illustrate how her friends shared in her rehabilitation milestones by decorating her room with pictures, stickers, glow in the dark stars, and a "Countdown Until Halo Free" poster.

We hung glow in the dark stars in the room and hung posters and cards on the walls. We had different signs. We made a "Countdown Until Halo Free" poster that we put a sticker on every day.



Figure 4.7 Tatiana’s Rehabilitation Ward hospital room



Figure 4.8 Tatiana’s “Countdown Until Halo Free” poster

Edie also spoke of the importance of friends and family during her hospital stay and how they supported her by always bringing small gifts, sitting with her and making her stay in rehabilitation as comfortable as possible.

I can remember I'd go to sleep and I'd wake up and there'd be some flowers or a new card beside me, it was like "where'd those come from?" It took me a little while to figure out who was dropping off these cards and stuff ... my room got filled with teddy bears and cards and stuff like that pretty fast.

The participants described the initial impact of their spinal cord injuries as traumatic, the healing process as exhausting and rehabilitation as challenging. With the support of family, friends and peers, the participants were able to move steadily toward the completion of rehabilitation enabling them to continue with the next chapters of their lives. This included going home to their family, friends and communities.

4.2 Learning To Be Me

Learning to be me describes the feelings and emotions the participants were going through during the transition from in-hospital rehabilitation back to their homes with family and friends. Tatiana's emotions surfaced as she talked about her conflicted feelings following her first afternoon visit home before being discharged from the rehabilitation ward. She felt very close to the people she came to know in rehabilitation. Leaving for home was a long sought goal, and yet she described how leaving behind people who had cared and supported her was very difficult (see Figure 4.9 and 4.10).

My first time home, I came home with my halo on, for a visit. I had to take First Bus (wheelchair accessible bus) and stayed for supper and then I had to go back (to the hospital). I was in tears. The very last day I was in the hospital I was going to be with my favourite nurse, my mom bought us water guns; we had a water fight on the ward!



Figure 4.9 Tatiana's first visit home, with her brother

Tatiana describes how she felt happy and excited to be home and yet scared and apprehensive to leave the security of the rehabilitation ward where there were professional staff who knew how to care for her as someone with a spinal cord injury. Going home had always been the goal, but the rehabilitation ward had become a very comfortable and safe place where the reality of the outside world was never a concern. Tatiana also reminisced about the close relationships formed with the nursing and therapy staff during her months of intimate time in rehabilitation with these professionals.



Figure 4.10 Tatiana’s water fight on her last day on the ward with her favourite nurse, a friend and a fellow patient with a spinal cord injury

This was a time of adjustment for the participants as well as for their families and friends. While participating in rehabilitation, the participants worked with their therapists to become as independent and self-sufficient as possible. However, as soon as the participants were discharged from in-hospital rehabilitation they felt they were hindered from furthering their goals of becoming independent. They felt their family and friends were providing too much help, albeit unintentionally. Two sub-themes, I need to do this on my own and too much help emerged as the participants strove to regain a level of independence similar to what they had prior to their injury.

4.2.1 I Need To Do This On My Own

The participants, although excited to be returning home, were apprehensive about leaving the hospital, the only environment they knew since sustaining their injuries. They were about to venture into an unfamiliar environment at home and in the community. At home, there were

friends and family but no nurses or therapists if something went wrong. The rehabilitation ward was a very secure and safe environment, which was staffed with professionals who were competent in dealing with spinal cord injuries and knew how to handle unpredictable complications that may suddenly arise.

Although the participants were striving for independence and were excited about returning home, there was an underlying “fear of the unknown.” Bree’s comment upon her discharge from the hospital was, “I didn’t want to leave the hospital...I just felt so comfortable there.” Tatiana added, “You come home and you’re used to being in the hospital and there’s all this new stuff (at home) and it’s overwhelming and frustrating, but it was great to be out!” Figure 4.11 depicts Tatiana in her living room at home while she is still in her halo traction.

Tatiana further described what it was like to learn about and live with her “new” body now that she was a quadriplegic. Her physical ability had been altered dramatically. Once a young vibrant swimmer, she now had difficulty putting on her own socks. Tatiana describes her body as “foreign” and something she had to “get use to.” She no longer had control over her body and how it physically functioned. Everyone saw her as the same person, just sitting down. They did not see whole picture of what it is really like to live with a spinal cord injury and what really happens behind closed doors. Tatiana describes these emotions during her transition home after leaving the hospital as “frustrating” with “lots of tears.”



Figure 4.11 Tatiana at home from the hospital

Tatiana spoke of the incredible and balanced support she had from her parents to help her through these times of frustration. Her dad was there and saw the frustration but “was still dad” and therefore did not help with personal care issues. He did help with many other issues Tatiana faced as she struggled to become more independent and self-sufficient, such as building ramps to gain access to their home. Tatiana’s mom was always there and during the height of many periods of frustration she would say, “Tatiana, patience, you’ll get it”, to which Tatiana’s replied:

I don’t want patience. I want to be able to go to the bathroom, I want to be able to get out of bed, and I want to be able to put my pants on by myself so I can go out for more than four hours with my friends.

Tatiana continued by explaining the learning process she was forced to go through to understand

her “new body” and how to face and overcome the challenges she was dealing with.

You’re body is part of you and you have to get use to it. It’s foreign to you. You have to learn how to work with it. You have to learn how to go to the bathroom, and how to transfer. It was a transition, a smack in the face, like “Oh my! Guess what? This is my body and this is what it’s going to be like now!” You can’t control it. You have spasms. The kicking legs suck. You have a bladder that has spasms, you have to drain it. Cathing sucks sometimes. I have stomach problems. I have to do bowel care and it doesn’t always work out. I know what I want and that’s the thing with a spinal cord injury...you’re still the same person. Everyone says, “This is the same Tatiana as before her accident. She’s just sitting on her butt”. That’s true, but they don’t see the spasms, the bladder problems and the personal stuff, it’s not just something you go and share with everybody. It’s more than just the chair.

Tatiana identified many issues touched on by the other participants as they struggled to regain their independence and sense of self when they first returned home following their time in rehabilitation. Susan added to this discussion when she shared her thoughts on what independence meant for her as someone living with a spinal cord injury.

You have to learn a new way to do things and you learn how to deal with people. You’re just put in situations where you have to stand up for yourself. Before (my spinal cord injury) I got anybody to do anything for me that I didn’t have to do myself and now I want to be independent and I’m forced to be in situations where I have do to do things on my own.

After Bree had been home for a while, she reflected on her time in rehabilitation and began thinking about her own independence. There were many tasks and skills, such as transferring in and out of her wheelchair independently, preparing meals and driving that Bree still wanted to learn and perfect.

Bree recalled:

I thought I did pretty well while I was in (rehabilitation) but of course after you get out you realise that a lot of the stuff that they teach you isn't that practical. Everybody always said they learned so much more after they were discharged and actually out doing stuff on their own.

The participants all stated that they quickly became comfortable with their home environments, allowing them to focus on what they needed to learn to become more independent. Bree was focused when she returned home. She worked hard on becoming stronger and more self-reliant, practicing tasks such as transferring her body to and from her wheelchair to the couch and back again as depicted in Figure 4.12.



Figure 4.12 Bree transferring from sofa to wheelchair

Eddie concurred with Bree and the other participants, stating her desire to be as independent as possible while not relying on others to help her with daily tasks. “I don’t really like relying on people to do stuff for me. I like to do it myself so getting stronger and being able to do transfers and push myself around was important to me.” Determined to be as independent as possible, one of Eddie’s first goals was to drive a vehicle. To accomplish this goal, Eddie needed to learn how to transfer from her wheelchair into a vehicle and then load her wheelchair into the vehicle as well (see Figure 4.13). Eddie continued, “I think my transfers are better. I’m much better at getting my chair into the car than out of the car.”



Figure 4.13 Eddie transferring into her car

The participants were very quick to acknowledge the support their families provided in their goal of independence by making wheelchair accessibility accommodations to their homes (see Figure 4.14). Tatiana stated:

My extended family was great. They built a ramp at the lake at the cabin and they carried me up and down in the farmhouse. My uncle built a ramp out at the farm for one of the

flights of stairs outside and they built a ramp at my step grandpa's house.

Tatiana's comments mirrored many of the participants' comments describing the incredible social and emotional support they received from friends and family as they began to venture out into their communities. An example of this support is the ramp Bree's parents constructed at their home, much like the ramps Tatiana refers to at her extended families homes (see Figure 4.19). Bree's parents built a ramp with a gradual enough slope allowing Bree to access her home independently.



Figure 4.14 Bree's wheelchair access into her parent's house

4.2.2 Too Much Help

The participants spoke of how, at times they felt somewhat frustrated with their family and friends when they first returned home from in-hospital rehabilitation. They felt they were receiving too much help from those closest to them. Although they were grateful and appreciated this assistance, they also felt that too much help interfered with their goals of becoming as independent as possible. Many of the tasks they were striving to accomplish were an extension of

the tasks they had begun learning in rehabilitation, such as dressing themselves, building endurance and strength through wheeling, and completing tasks around the home. As the participants faced these challenges, their family and friends found it difficult to sit back and watch them struggle, when they could easily assist them. Bree felt she received too much help from her family and reflected:

I guess my dad's the worst for doing stuff for me that I can do myself. If we're going in some place I'll push myself and he'll walk along behind me and start pushing me and I'll have to tell him to back off.

Tatiana added to this by describing an experience she had when someone wanted to assist her by pushing her chair for her. She said, "Don't touch my chair, I'll push myself, thank you very much, I'll get it...I will get it."

Although the participants' friends and family were always there to help, encourage and support them, they sometimes became inhibitors, preventing the participants from working through things on their own, while learning a new task. At times, when the participants struggled through a new and sometimes difficult task, such as learning how to get in and out of a car, family and friends would offer too much assistance, resulting in frustration towards family and friends. Edie recalled her mother being over protective and stated mom was "being all mommyish and wanting to help ... and you're just like 'can I do it myself please?'"

4.3 Getting Back To Life

After the participants had been home from rehabilitation for approximately 12 months, they felt as though they were able to begin getting back to life. To this point, the participants had spent much of their time learning how to live with a spinal cord injury by working on the

necessary skills required to live independently, some of which included transferring into a vehicle, transferring into and out of bed, preparing meals and learning how to manage their personal care. As the participants continued to work on improving these skills they also began focusing on other aspects of their lives. Getting back to life included participation in physical activities that were fun, rewarding and positive. There was a shift from their rehabilitation mindset to a new sense of identity that provided the participants with feelings of accomplishment and validation as well as a sense of having control over who they were and where they were going.

Getting back to life was an expression of accomplishment and validation. Participants spoke of getting back to life as they felt more comfortable with their spinal cord injuries and continued to build their physical strength, which in turn helped build their self-confidence to accomplish daily activities on their own. Physical activity became an important and integral component of everyday life, and was reported to impact the participants' abilities to regain their independence. The participants also spoke of how their involvement in physical activity and disability sport provided opportunities to socialize and meet many new people who had sustained similar injuries, had been through rehabilitation, and were willing to share stories and information about life with a spinal cord injury. Through these new contacts and friends, the participants reported being able to grow, learn, and share their own stories and experiences with others.

4.3.1 Validation Through Physical Activity

The participants all mentioned that they had been exposed to physical activity opportunities in their communities through their recreational therapy sessions while in

rehabilitation. They were also interested in pursuing physical activity opportunities once back at home. Tatiana was physically active prior to her spinal cord injury and realised the benefits of physical activity. She believed that if she continued to be active from a wheelchair, she would be able to increase her level of independence and maintain her health.

If I gain weight, if I can't do those transfers, if I'm not healthy, I don't know how I'd have independence. I need to be healthy. I need to be active.... I think by just being active you're going to keep your body healthy and strong because you can increase your independence. I strongly believe that I do need to be active to stay healthy, to keep the blood flow and to keep my oxygen levels up. I've noticed huge differences when I'm active. I'm not saying competitive sports, just being active, at whatever level. When I start training and doing weights full time I'm doing things even better. I mean I feel better and my transfers improve.

Edie also recalled, "I'm more physically active now than I was before. I feel satisfaction knowing I went out and did something good for myself. I think it's important for my overall health." Gabriel, another participant, concurred with Edie's comments stating, "After I started trying different sports, I felt like my health got way better. [Before I was active], I was sick a lot. I didn't do very much. When I started doing physical activity my health improved a lot."

Bree also recognised the benefits of physical activity soon after returning home from rehabilitation. Upon Bree's return home, she, Gabriel and a few others started a small workout group for people with mobility impairments at a local community fitness centre. Soon after this small group began meeting, Edie joined as well as Tatiana, who was already involved in physical activity through sport. They agreed to meet together on a regular basis. Bree's goal was to

continue a physical exercise program similar to what she had been taught in rehabilitation through weightlifting and cardio exercise. Bree soon saw the benefits of regular physical activity. “The workout group has really helped me to get stronger and now I am able to do some of the things I was really apprehensive about before, like if I fall forward (in my wheelchair) now I can get myself back up.”

Tatiana went on to say:

Sports took over from rehab and that’s another way to become more independent. I find day-to-day things so much harder to do now [than when I was able bodied] and so that’s helping me get that independence that I’m looking for and I want because I need the endurance and the strength just to be able to do stuff.

Eddie concurred with both Bree and Tatiana as she too wanted to increase her level of independence and felt that physical activity was an ideal way to make this happen. “I wanted to take up a sport to begin with to get in shape because I figured it would help me with transfers and just activities of daily living.” The participants believed physical activity was important for their health as a means to increase their independence and improve their quality of life.

Tatiana, Bree, Gabriel, and Eddie were interested in taking their physical activity pursuits further and began exploring organized sport at a competitive level. Becoming involved in wheelchair sports at a competitive level was a natural progression for these young women. Before choosing one particular sport to focus on, they tried many wheelchair sports including wheelchair rugby, wheelchair basketball, wheelchair tennis, (see Figure 4.15) wheelchair skiing (see Figures 4.16 and 4.17), and wheelchair racing. The more activities these young women tried, the more they enjoyed physical activity for its own sake, while also recognizing the

important role that physical activity during rehabilitation played in their recovery and preparation for physical activity and sport pursuits.



Figure 4.15 Edie receiving instruction from the tennis coach



Figure 4.16 Tatiana water skiing



Figure 4.17 Gabriel with her coaches, cross country skiing

Stories shared by the participants' revealed how physical activity and sport became a competitive passion for them as they moved from physical activity for the purpose of rehabilitation to participating in sport at a competitive and elite level as seen in Figures 4.15, 4.16, 4.17, as well as on the following pages in Figures 4.18, 4.19 and 4.20. Physical activity became a part of the participants' everyday lifestyle and they believed it increased their quality of life as someone living with a disability. Tatiana explained:

(Sport) made a huge difference for me. Socially it's fun. I get to travel, I can transfer now; I'm getting more strength and endurance. I can make it up ramps, I can do things I was never able to do on my own. The way sport has changed my daily living is huge!

Tatiana shared her initial experiences and first impression of wheelchair racing. She recalled, "The first time they tried to put me in [a racing wheelchair or track chair] I swore it off and said 'I'm never doing this again!' Well, they convinced me to go back the next day." Soon

thereafter, wheelchair track became one of Tatiana’s passions (see Figure 4.18). Tatiana had never looked back and believed wheelchair racing has been beneficial for her and has enhanced her life.

I kept going with it and just kept on training and it pushed me. I started learning to transfer much better. My daily living activities, which I couldn’t do before, like getting into a vehicle, I can do now and I can get into my shower and get into bed.



Figure 4.18 Tatiana loving wheelchair racing

Bree had an opportunity to compete at a national Wheelchair Rugby competition soon after she had returned home from rehabilitation. She was excited about this opportunity as her goals included becoming involved in wheelchair sports. “Rugby was awesome. I’ve been playing sports my whole life and I’ve never actually competed at a National level with anything.” Figure 4.19 is a picture of Bree competing at her first National Wheelchair Rugby Tournament.

As the participants became comfortable in their environments and continued to focus on

their independence, they began feeling better about themselves. Gabriel summed up her experiences with physical activity and sport as someone with a spinal cord injury nicely in a few words when she stated she felt, “more confidence in me and who I am...better self esteem.”



Figure 4.19 Bree and her team mate playing Wheelchair Rugby

Edie added to Gabriel’s thoughts sharing that she felt sport involvement made her more comfortable with who she had become (see Figure 4.20).

I consider the accident really changed me for the better. I’m much more positive than I was before. I’m more socially involved than I was before. And it’s just helped me come more to terms with who I am.

The participants continued to enjoy their experiences with wheelchair sport and began training and competing against others with similar disabilities from across the country and around the world. The more they trained and competed, the more life changed for them. Activities of daily living such as transferring, dressing, and living independently became easier. Opportunities to travel, compete and meet others from around the world became a reality.



Figure 4.20 Edie in her racing wheelchair

Physical activity and sport became an important part of the participants' lives and they believed being physically active improved their quality of life. The participants' wanted to share this information and their experiences with physical activity with others who had recently sustained spinal cord injuries (see Figure 4.21). By sharing their experiences with those who were in rehabilitation, the participants came full circle. They began their journeys as individuals who had sustained a spinal cord injury and were in rehabilitation receiving information and learning from others in the community, and grew into people who were willing to share their experiences with other individuals with recent spinal cord injuries. In the following section, the participants discuss the opportunities they had to learn from others with spinal cord injuries and their desire to do the same for newly spinal cord injured persons going through rehabilitation.



Figure 4.21 Tatiana sharing her experiences with someone going through rehabilitation

4.3.2 Learning From Others

A strong message which came through in my discussions with the participants' was the appreciation and respect they had for others with spinal cord injuries who were willing to share their experiences with them. The participants discussed how they gained a great deal of knowledge and confidence from the many people they met. Tatiana spoke of the willingness of others with spinal cord injuries to share stories with her including everything from preparing a meal to travelling around the world and competing in sport. She recalled:

Being a part of the wheelchair community has really benefited me because I get to talk to people who have gone through the same things as I have. They just came and talked to me and laid it out.

Bree agreed with Tatiana and also found the support and role modeling of people in the community with spinal cord injuries to be very helpful. Bree felt very fortunate to have met Chantal Petitclerc, one of Canada's outstanding wheelchair sports athletes at a fundraising event

for athletes with spinal cord injuries.

In addition to the opportunity to learn from others, Bree appreciated the social interaction with others who were in a similar situation as her:

[Meeting others with spinal cord injuries] was very beneficial, not just the physical benefits but also just learning that everybody else has been through the same thing and everybody's really helpful. I couldn't figure out how to do some stuff on my own but talking to people [with spinal cord injuries] who would tell me how you do it and what makes it easy . . . that definitely helped a lot.

Gabriel also remembers her first encounter with wheelchair sports as a girl with a spinal cord injury growing up in rural Saskatchewan. There were no other people where Gabriel lived who knew much about spinal cord injuries. She felt quite isolated and recalled her first experience with wheelchair sports:

I didn't really know what was all out there or what kind of sports I could play or participate in. I kind of thought that if you had a spinal cord injury you couldn't really do much physical activity. I do remember seeing Rick Hansen on TV and learning about him. That impressed me and I wanted to learn more about sports and stuff after I saw that. Probably because he was the first person I saw in a wheelchair that was physically active in a big way. That impressed me.



Figure 4.22 Gabriel with Rick Hansen

Gabriel has since become very active in many wheelchair sports including cross country skiing and wheelchair racing. She has also become a leader and a coach for wheelchair basketball providing opportunities for many young people with mobility impairments across Saskatchewan.

Tatiana met many people through her travels as a successful wheelchair racing athlete. She spoke about the information she gained through candid conversations with people living in the same situation and experiencing the same daily struggles as her. Tatiana believes sharing information with her peers has been extremely beneficial. Topics discussed included, “How do you go pee?”, “How do you get dressed?” “Now let’s talk about showering.” She recalled, “Everyone does things differently and that’s been so helpful, so beneficial.”

Comments such as Tatiana’s were echoed by all the participants. The believed physical activity was so important for their physical and mental health that they felt compelled to share their experiences with others living in similar situations. All of the participants were very open and willing to share the stories of their journeys with me. Their journeys told the story of what it

takes to thrive after a spinal cord injury. I felt very privileged to have had the opportunity to spend time with my participants and hear their stories. I felt as though I was with them while they were in rehabilitation, as they transitioned back to their homes and as they regained their independence and were able to “get back to life.” I hope these abbreviated stories of the participants’ journeys, which I have shared with you have been as inspirational for you as they were for me.

5.0 DISCUSSION

Having sustained a spinal cord injury, I have experienced how dramatic life can change in an instant. I had just completed grade 11, school was out and summer had just began. My whole life was ahead of me and then in a fraction of a second, I zigged instead of zagged. Crash! I was lying in the ditch, thrown from my car. Fast forward and I am in the hospital intensive care unit with a cervical 5-6 spinal injury. I had crushed my spinal cord in my neck and was a quadriplegic. At the time I had no idea what that meant. I had never known anyone in a wheelchair and never dreamt of needing one myself. Now I was a quadriplegic with no lower body function and little upper body movement. I was facing six months of rehabilitation and an intense life adjustment. No more hockey, ball or swimming. How could I work, where would I live, how will I drive? These were just a few of the thoughts that raced through my mind in the days, weeks and months following my spinal cord injury.

Although the discussion chapter is based on the experiences of the participants, I strongly related to their stories. The commonalities in the participants' experiences and my self-reflection confirmed for me that the stories I heard were reflections of their experiences. The stories shared by the participants described their spinal cord injuries, rehabilitation processes, and experiences with physical activity while in rehabilitation and following their return home. I will discuss the participants' experiences following their spinal cord injuries and the common threads that bring together their unique yet similar lived experiences (Van Manen, 1997).

The stories shared by the participants bring to life the full scope of Rimmer's (1999) health promotion model for persons with disabilities. The participants spoke of their bodies healing, of learning skills that enabled them to gain independence, and the supports needed to

applying those skills in community physical activity settings. The findings of this study illuminate the role of physical activity in rehabilitation based physical fitness; how it contributed to the physical activity and sport pursuits of these participants following discharge, and the participants' desire to share their experiences of physical activity with those with newly acquired spinal cord injuries. The participants' experiences highlight the gap in health-promotion services that were available to the participants of the study. The "middle section" of Peter's Health Promotion Model for People with Disabilities was not available to the participants as they did not experience Clinically Supervised Health Promotion through hospital based or university based fitness facilities following hospital based rehabilitation. My research findings are reflective of earlier work completed by Vissers et al., (2008) who looked at the barriers to and facilitators of physical activity immediately following in patient discharge for someone with a spinal cord injury.

5.1 As My Body Heals

The experience of disability can have a severe and profound effect on many different facets of an individuals' life. Sustaining a spinal cord injury is what Schlossberg (1995) and colleagues would refer to as an event trigger that creates the need to transition to new life circumstances. Each participant faced a number of challenges as they entered rehabilitation and began the long transition back to life in their home communities. The first emergent theme, as my body heals, reflected the participants' experiences while they were on the rehabilitation unit in the hospital. The participants identified this as a period of significant physical and psychological healing as they were physically exhausted and emotionally overwhelmed. Initially, there was little opportunity for physical activity as their bodies were healing from the physical

trauma of their injuries. Their injuries drastically altered the participants' ability to physically move their bodies, thus limiting their bodies' structure and function, resulting in impairment (Peters, 1996). As the participants began to regain their physical health, they soon realised that the changes in their ability to move their bodies, significantly altered their ability to perform activities the way they had prior to their spinal cord injuries. Situational variables such as length of time in the neurological ward impacted how soon they could begin their transition to the rehabilitation ward where they would learn skills that would enhance their independence.

Combined with adjusting to physical changes, the participants were also confronted emotionally with the reality of living with a disability. This realization created a period of emotional adjustment as the participants faced the psychological challenge of living with restricted bodies and changed abilities. These findings support what was found by Schlossberg, (1991) and how humans cope with traumatic life changing events. The participants were now required to relearn how to live with their new disabling conditions. Facing the realities of disablement and restriction of abilities with the psychological and emotional realities of how their bodies now functioned changed their lives. Peters (1996) refers to the interaction of the changes in structure and function of the body with a new sense of self as the impairment plane of disablement. The psychological challenges they experienced were evident in the participants' stories of learning and relearning to enhance their physical independence. Small tasks had become huge challenges.

5.1.1 Everything Is A Challenge

Rehabilitation became a place where the participants began rebuilding themselves both physically and emotionally as they adjusted to their new lives as individuals with spinal cord

injuries. Looking within and confronting the physical changes they had experienced was described as one of the first real challenges the participants faced Schlossberg (1991). These changes included the physical, structural and functional changes of their bodies, such as how they had lost the ability to control and move their arms, legs and torso and what this meant. The participants were learning how to move their bodies using the remaining function and physical strength from the parts of their bodies that were undamaged. This remaining physical function varied from participant to participant as they each experienced a different level of spinal cord injury (i.e. partial use of arms and upper body to full use of arms, upper body and some lower body function). These findings are reflective of the initial research by Harvery, Lin, Glinsky & De Wolf (2009) examining the effectiveness of physical therapy interventions for people with spinal cord injuries.

The regiments of in-hospital rehabilitation forced the participants to face the physical and emotional challenges of living with a spinal cord injury. They had to address the dramatic structural and functional changes of their bodies. They no longer had the use of the bodies they had once known and had to adjust to living life with a spinal cord injury. The participants adapted to their environments as individuals in wheelchairs without the full use of their bodies by pulling upon personal and psychological resources (Schlossberg, 1991). Gill (1997) referred to the process of learning about integrating the ‘new’ body with an emerging sense of self as coming together. The strong areas of the body became integrated with the weaker areas to create a new sense of the physical self as they learned or relearned grooming, transferring and bathroom skills. Gill (1997) suggested that “coming together” is a process of emotional acceptance that individuals with a disability may experience as they begin to adjust to the differences in the structure and function of their bodies, that is how their bodies once functioned prior to

disablement or in relationship to the able-bodied population. Gill (1997) does not address the concept of physical activity when she identifies coming together as a process of emotional acceptance. One might assume that an individual who has accepted who they are regardless of disability may feel more physically comfortable and confident in their physical activity pursuits.

5.1.2 They Were Always There For Me

Stories of support were clearly evident throughout the participants' discussions. Parents, friends, and rehabilitation professionals provided support as the participants transitioned from the neurological ward to that of rehabilitation. The types and function of supports are integral to the transition process (Schlossberg, 1991). The participants highlighted two types of support: professional support and the support of family and friends. The professional or interventionist support took the form of rehabilitation therapists and nurses who were very knowledgeable about spinal cord injuries (Peters, 1996). Family and friend provided love, encouragement, and a social link to life outside of the hospital setting. The two supports also had distinct functions. The rehabilitation professionals provided the structure and knowledge for learning skills and regaining independence, while family and friends provided the motivation for achieving independence, that being returning home or completing the transition process (Schlossberg, 1991). Although physicians were also part of the in-hospital rehabilitation context, they were not present in the participants' discussions of the time their bodies spent healing. It may have been because they were not perceived to be integral to their physical and psychological healing process – but rather provided medical support, some of which occurred when the participants were quite ill. The role played by the medical professionals in my research supports the findings of Cott, Wiles, & DeVitt, (2007) in their discussion relating to the transition of rehabilitation to

community following a disability.

The participants' physical therapy included strength and conditioning as well as endurance training under clinical supervision toward the goal of functional independence. The presence of physical fitness as a component of hospital rehabilitation supports the health promotion model for persons with disabilities presented by Rimmer (1999). Physical activity was introduced early in the rehabilitation process, even while healing at the site of the spinal cord lesion was still occurring (i.e., halo brace still present). Achieving independence on benchmarks skills (e.g., wheelchair transfers) were dependent upon having sufficient strength to safely and reliably complete the tasks. In-hospital rehabilitation provided the equipment, clinical supervision, and social supports needed to accept functional changes in the movement of the body and learn new ways of doing things. These findings are reflective of earlier research conducted by Harvery, Lin, Glinsky & De Wolf (2009) as they began to explore the effectiveness of physical intervention for people with spinal cord injuries.

Maintaining and strengthening themselves became a major focus of the participants' individual rehabilitation programs. Each participants' rehabilitation program was individualized to suit their needs and included strength training with weights, aerobic training with hand ergometers and mat work with their therapists. The mat work was described as a physically challenging and fatiguing task. The participants were learning how to move their bodies from their wheelchairs to raised mats while simultaneously learning how to reposition themselves and lift their legs onto the mats.

Other key supports for the participants came from their family and close friends. Peters (1996) model of disablement designates those that are not active members of the medical process of rehabilitation as outsiders or people who are observers of disability. Interestingly however, as

family and friends knew the participants intimately prior to their spinal cord injury, they provided the type of support that no one else could. The participants' family and close friends became intimately involved in the physical, social and emotional adjustment of the participants throughout the rehabilitation process, even to the extent of joining them for their exercise sessions. They related to the participants not as someone with a disability, but as a person who was healing from an injury. This type of support appeared to have been integral to the participants' motivation to keep moving forward during rehabilitation so they could ultimately return home to family and friends. Family and friends also provided the participants with someone to lean on during difficult times Schlossberg, (1991).

The active support provided by family and friends during exercise sessions is reflective of what Rimmer (1999) referred to as clinically supervised health promotion. The participants were provided with prescriptive exercise by the therapists in an environment with adapted fitness equipment. The programs were completed with family and friends, however, thereby increasing community presence into the rehabilitation process. It could be argued that having *outsiders* present is an effective strategy for preparing people for full transition (Schlossberg, 1991).

Peters' (1996) model discusses the interaction of body, person and society and the extent to which activities and participation in preferred activities are impacted – or the process of disablement. The early stages of rehabilitation for the participants of this study were focused on the body and coping with the new challenges in how that body moved and functioned. The emphasis on regaining independence and learning needed physical skills in rehabilitation supports the tenets of Rimmer's (1999) health promotion model. Rimmer suggests that therapy and the rebuilding of an individuals' physical function following trauma plays an important role in the rehabilitation process. The participants' motivation to become stronger and gain

independence through rehabilitation supports Peter's (1996) model of disablement and Rimmer's (1999) health promotion model. Both models acknowledge the functional changes that can occur with impairment and advocate for support systems to be in place to facilitate the transition from rehabilitation to community engagement.

5.2 Learning To Be Me

At home, in their communities, the participants were faced with the reality of living with a spinal cord injury in the 'real world,' unlike the protective environment of the hospital rehabilitation ward. The participants stated they were excited about returning home to their families and friends, but were also apprehensive about leaving the security of the hospital environment and their perceived ability to cope with the new surroundings (Cott, 2004; Cott, Wiles, & Devitt, 2007). On the rehabilitation ward, the participants felt comfortable and familiar with their environment. There was a sense of security in knowing the nurses, doctors and therapists were close by and were trained to handle unpredictable complications related to spinal cord injuries. The rehabilitation ward had been home for the participants since their spinal cord injuries and was a place that felt very safe and comfortable. As excited as the participants were to be returning to their homes in the community, with their changes in physical function as a result of their spinal cord injuries, their homes were now unfamiliar environments that initially did not feel as secure as the hospital. This was a time of change and mixed emotions described by the participants as overwhelming and exciting all at once, as the participants learned strategies to interact with their new physical and social environments. These findings are reflective of earlier work by Cott, Wiles, & DeVitt, (2007) examining the transition to community following a stroke.

5.2.1 I Need To Do This On My Own

Experiencing what it was like to live outside of a hospital environment and in the community with a spinal cord injury was exciting but marred by frustration when the participants realised that they did not have the strength, capability, or technique to be completely independent. They realised that there was so much more for them to learn in order to function independently in the world around them. The situational variables changed as the participants transitioned back to their homes that required adjustments to bathroom and kitchen configurations and shared family living spaces. Schlossberg (1991) spoke of the importance of strategies in coping with changes brought about by situational changes. Independence was a strategy that participants enlisted as they learned about who they were. The participants' desire to complete tasks independently as they transitioned from the rehabilitation setting to home was also reflective of Gill's (1997) disability identity development experiences of coming to feel I belong. Achieving independence and learning to apply the skills learned in rehabilitation without the support of rehabilitation professionals was important to the participants' sense of belonging in the community.

As key support people, the participants' families and close friends spent not only a great deal of time with the participants throughout the rehabilitation process, but also provided support following the discharge from the in-patient rehabilitation ward. This was a difficult time for the participants' family as they had to sit back and watch their daughters struggle with the many tasks they were trying so hard to learn such as dressing themselves and transferring to and from their wheelchairs independently. The participants knew additional assistance to achieve tasks would make life easier in the short term, but they also knew that their families would not always be around to provide assistance. If the participants were to become independent, they knew they

would need to learn the many tasks required to live in a wheelchair with a spinal cord injury. The self they knew in rehabilitation underwent a transition as they returned home. They needed use their inner emotion strength as well as their physical strength to accomplish the goals they had set out for themselves (Schlossberg, 1991).

The participants did not speak of sadness or depression in returning home, although their stories of how their bodies were foreign, something to be gotten used to, and tears suggest that it was an emotional time. Staying connected to family and friends through shared leisure experiences has been reported to reduce depression (Loy et al., 2002). The participants were able to maintain their connection with their extended families as ramps and other physical supports were put in place. Lack of equipment and architectural barriers can decrease independence and level of physical activity of persons leaving rehabilitation for up to 12 months post discharge (van den Berg-Emons et al., 2008). Fortunately for these participants, the strategy of keeping connected with extended family through the building of ramps was implemented even prior to discharge from hospital in some cases (Schlossberg, 1991).

5.2.2 Too Much Help

While independence at daily tasks was paramount to the participants, they also realized that they needed their family and friends. Independence with daily tasks at times required understanding from others. Spinal cord injury was more than using a wheelchair for mobility. Muscle spasms, bladder and bowel issues, personal care concerns, and fatigue were also part of the independence equation. A great deal of learning occurred for the participants and those closest to them during those months following discharge from the rehabilitation hospital. Within the rehabilitation context the interventionists (i.e., therapists) understood the importance of

independence in daily activities, how much assistance to provide and when not to provide assistance at all. Outsiders understood the need and desire for independence less well (Peters, 1997). Functioning independently meant learning how to cope with others around them, who at times offered too much help. The participants recognized and appreciated the assistance they were receiving from their families but “over helpfulness” was a barrier to their independence (Vissers et al., 2008). At times, the participants’ family members became inhibitors and were actually preventing the participants from working through tasks on their own. The internal conflict the participants were dealing with combined with the tension between themselves and their families created stress for the participants (Schlossberg, 1991). The participants’ rejection of help reinforces the conflict that overzealous support of others can create, particularly by well meaning members of the public (Goodwin & Thurmeier, 2004; Goodwin, Johnston, Gustafson, Elliott, Thurmeier, & Kuttai, 2009).

5.3 Getting Back to Life

Independence in their daily activities and self care was considered essential to integration into society as a person with a spinal cord injury. At the same time, the participants found acceptance and a sense of community with persons with disabilities through disability sport. Through disability sport participants found a sense of community and the opportunity to share life experiences with others with spinal cord injuries, found companionship, and learned from others who had ‘been there.’ Identifying with the disability community was referred to by Gill’s (1997) as coming home.

5.3.1 Validation Through Physical Activity

The initial introduction to physical activity through hospital-based therapeutic recreation was described by the participants as the beginning of a new and exciting lifestyle that incorporated physical activity as part of a daily routine. During rehabilitation, the participants were exposed to a variety of physical activities including archery, fencing, tennis, athletics, basketball and wheelchair rugby. This early exposure, according to the participants of this study, highlighted what was possible and set the stage for future participation (van den Berg-Emons et al., 2008).

Rimmer's (1999) model of health promotion for people with disabilities supports the introduction of physical fitness and physical activity for people with disabilities in clinical settings. Linking the services of rehabilitation centres and community fitness facilities emulates the four factors that influence a person's ability to cope during transition – situational variables, the self, supports, and strategies (Schlossberg, 1991). The situational variables of role change, time in rehabilitation, and the sense of loss that occurs with spinal cord injury were supported through the rehabilitation process. Rehabilitation appears at the top of Rimmer's (1999) model. Through rehabilitation, the participants gained a sense of self and came to terms with their readiness to engage in physical activity. Rimmer suggests the process of developing confidence and self-esteem requires clinically supervised health promotion. By providing this form of support, re-entrance into the community can begin, and supports can be put in place. These findings support what was found by Cott, Wiles, & DeVitt, (2007).

Making these community connections and becoming involved in physical activity at a community level with peers provided an environment for the participants to continue to recovery from their spinal cord injuries, both physically and psychologically (Vissers et al., 2008). The

physical benefits as noted by the participants included increased physical strength and function, which increased their mobility and ability to carry out their activities of daily living, such as transferring to and from their wheelchairs. The psychological benefits identified by the participants included feeling better about themselves and an increased sense of self esteem. The participants' comments and experiences concur with the literature, which states that people with spinal cord injuries who participate in physical activity have realised both physical and psychological benefits (Ashton-Schaeffer, Gibson, Autry, & Hanson, 2001; Henderson & Bedini, 1995).

In the instance of the participants of the study, the supports required to gain the confidence to be independent and physically active were provided in the clinical setting of rehabilitation. The rehabilitation professionals designed therapy programs and encouraged friends and family to join the person with the spinal cord injury in their sessions aimed at increasing strength and fitness. The recreation therapists also provided exposure to others with disabilities who demonstrated disability sport during their in-hospital rehabilitation. Opportunities to try out the equipment and sports were also provided at this time.

Ultimately, all the participants embraced fitness and a physically active lifestyle for reasons of health, fitness and enjoyment which is the culmination of Rimmer's (1999) health promotion model. Physical activity and sport pursuits validated the participants' sense of self, hard work they put into achieving community integration, and benefits of identifying with a disability community. The participants' experiences in physical activity settings concur with Gill's (1997) notion of disability identity development. The validation of 'who I am' and 'what I can do' as someone with a spinal cord injury was strengthened and confirmed through physical activity and sport.

The participant's stories of increased health, fitness, and social networks support the work of others who have documented the physical, social, and emotional benefits of physical activity for persons with spinal cord injuries (Carlson et al., 1999; Kavanagh & Shephard, 1990; Shephard, 1991).

5.3.2 Learning from Others

The participants indicated that their interest in physical activity grew and took shape very rapidly following their initial introduction to physical activity during rehabilitation. When the participants were discharged from in-hospital rehabilitation they began looking for physical activity opportunities for people with disabilities in the community. The connections they made and people they met during rehabilitation provided the initial contacts the participants required to get involved with physical activity in the community.

For many people with disabilities, the connections and relationships among and between others with disabilities have proven to be an invaluable source of information, support and companionship. There is a sense of sameness and ease when associating and talking with peers who have had similar life experiences and understand disability from an experiential point of view (Gill, 1997). Although Gill (1997) does not specifically explore disability identity development as it relates to physical activity and sport for people with disabilities, there are many parallels to general disability identity development that are found in disability sport. On many occasions, after becoming involved in physical activity, the participants described the benefits and knowledge they gained through these peer support networks. These were informal connections made with others who had experienced a spinal cord injury and were now also physically active in the community. Engagement in disability sport was a significant strategy in

the participants' successful transition to their home communities following a spinal cord injury (Schlossberg, 1991).

The participants who became involved in sport at an elite level traveled around the world, developed peer relationships, and extended their community physical activity experiences and peer relationships to a global level. At the local or global level, the relationships were important and created a new sense of self and personal pride in their achievements (Levins, Redenbach, Dyck, 2004).

6.0 CONCLUSION

As I conclude my research, I feel very fortunate to have had the opportunity to speak with the young women in this study about their experiences with physical activity and spinal cord injury and more specifically, about their experiences with physical activity while in rehabilitation immediately following their injuries, and throughout their transition back to the community. Physical activity was introduced to the participants shortly after their spinal cord injuries while in rehabilitation. As they moved back into the community, physical activity and sport became an integral part of their daily lives. The participants all agreed that physical activity improved their overall well being leaving them feel stronger and healthier with increased independence, self-confidence, and quality of life.

The participants shared their stories of how rehabilitation was a challenging period full of successes as well as setbacks and disappointments. Their physical capabilities changed dramatically following their spinal cord injuries as they were now living life on wheels and were forced to rebuild themselves physically and emotionally. The participants discussed how and what they learned and endured through rehabilitation, which made them physically stronger and emotionally capable of handling the obstacles they face as people with spinal cord injuries. Becoming physically active was part of that change and an important component of their new life.

Contributing to their journey from the trauma of a spinal cord injury to an active healthy lifestyle was the support of rehabilitation therapists that provided the skills and motivation to return home. Key to returning home was mastering the ways in which their ‘new bodies’ functioned and the gaining independence in daily activities. The participants had the emotional

support of family and friends both in rehabilitation and upon returning home. At times, their support was over zealous, creating tension and the need for the participants to self-advocate for their independence.

The fitness activities they participated in during rehabilitation carried over into their lives once home. Physical activity was important for maintaining strength, which was deemed important for maintaining the independence they had worked so hard for as part of their rehabilitation. The social networking that disability sport and physical activity provided enhanced the participants' sense of community while also bringing them in contact with others who could teach them strategies for independence. Physical activity was integral to the participants' disability identity to such an extent that they felt it was important to share their journey with others who were beginning their lives as people with spinal cord injuries.

The research process has been an educational one for myself as an insider and a researcher and remains unclear and unresolved in many ways as I reflect upon my research. One event that caused me to reflect upon my research was a journal I received from one of the participants' as an artifact. This was a journal written by the participant's mother and close friends of an account of her time in intensive care and rehabilitation following her spinal cord injury. The participant indicated that, at the time she was emotionally unable to read the journal herself. I did not read the journal as I felt the information contained in this document was not information the participant was prepared to read herself, let alone information that I could interpret and include in my findings.

I also reflect upon the prominence of the term "independence" used time and time again by the participants in their stories of their lived rehabilitation experience. From my vantage point, as someone who has lived with a spinal cord injury for many years, I wonder about the

term “independence” versus the term “interdependence”. Can the term interdependence only be possible after one has experienced self-defined independence as reflected in the results section, *Getting Back to Life*? Although the participants spoke a great deal about physical independence, which I believe speaks to the importance of the physical embodiment of spinal cord injury and physical wellness, I wonder about other forms of independence such as the emotional and psychological sides of independence reflected in the literature but not part of the participants’ stories. Within the context of the study, the participants spoke of their physical selves during this stage of their life journey as people with spinal cord injuries. As a person who is much further along in that journey, my perspective is perhaps broader, given the self-reflection I experienced as the researcher.

As the primary researcher, I was an insider, someone who has experienced disability first hand (Peters, 1996), in this case someone who had sustained a spinal cord injury with similar rehabilitation and lived experiences as the participants. I believe my insider perspective provided strength to my research as I was able to build a solid rapport and trust with the participants’ and relate to their stories and experiences. Although, at times I had concerns about my ability as an insider to hear the participant’s stories as “new” or “important”, rather than affirmation of my own experiences. I had originally put my voice into the presentation of the results and then removed it, stepping back and letting the voices of the participants speak for themselves. Yet, my study is interpretive, based upon my view of the world as a person with a spinal cord injury. I am not necessarily sure that I honoured my own strengths as an insider to the research. I know I was constantly vigilant in my analysis and presentation of the findings and used the support of your supervisor to talk through and review my writing. Is my research an accurate account or an

interpretation that may change with additional information? For now I have done my utmost to honor the lives of the participants through the stories they generously shared.

6.1 Limitations of Study

The following are limitations to the study.

1. The participants relied on recalled memories of their rehabilitation experiences. As memories fade, the more negative or emotionally difficult experiences may have been left out of their stories. A further study that followed people with spinal cord injuries through their rehabilitation and return to home journey in real time is recommended. Longitudinal studies focusing on spinal cord injury, physical activity and the transition from hospital rehabilitation to community physical activity participation is warranted.
2. At the time of the study, the participants who volunteered for the study were all female. Although this provided an all female perspective, the perspective of males is also needed.
3. The sample size of this qualitative study was small, and although I believe I reached data saturation (Creswell, 1998), further study with distinct sub populations of spinal cord injury is warranted. Although not apparent in my study, it may be argued that the experiences of people with paraplegia are markedly different from those with quadriplegia. Expanding the study to include rural residents should also be considered.
4. Expanding the criteria to include others with spinal cord injuries such as those who are older, as well as individuals who have been injured longer, would provide more in depth data on the same topic for an expanded population. I believe this data may be beneficial and would increase the knowledge base of the relationship between physical activity and spinal cord injuries. There is an aging population of people with spinal cord injuries who

may benefit from this research. An increased knowledge base may also be helpful for researchers, healthcare professionals, community physical activity specialists, and others involved in the field of health and disability.

5. One of the originally proposed components of this study was to gather artefacts from the participants, which represented physical activity during the retrospective timeframes of their lived experiences (van Mann, 1997; Creswell, 1998). The artefacts I received from the participants were very powerful and assisted the participants to retrospectively recall events from their time in rehabilitation as well as their transition into the community. Not all of the participants felt they had a significant artefact, which represented physical activity during the timeframe we were discussing. I believe further exploration and discussion with the participants about the artefacts may have provided more significant data in relationship to the research.
6. As a new researcher, I soon realized how not all research participants are equal. The content and quality of the interview material by different participants varies as much as the participants personalities. You will immediately notice throughout my study that there is a difference in the equitable voices of the varying participants.

6.2 Future Directions

The experiences of the participants of this study may not be representative of the relationship between physical activity and spinal cord injury for all people with spinal cord injuries. To gain a deeper understanding of physical activity as it relates to people with spinal cord injuries, further research needs to be completed. The following points identify recommendations for future research.

1. Future studies might include a larger sample population of people with spinal cord injuries from various demographic groups including: various age categories, geographic regions, levels of injury (i.e. quadriplegic, paraplegic), length of time since injury and levels of interest in physical activity. These various demographic groups have a vast amount of insider experience as people living with spinal cord injuries. Their knowledge and insight about physical activity and spinal cord injury may shed new light for researches and professionals about physical activity and spinal cord injury.
2. As important as the voices of persons with spinal cord injury are to our understanding of the transition process, the perspectives of other key stakeholders in the transition experience are also required, including: family members, healthcare providers, rehabilitation professionals and community physical activity specialists. These individuals played significant roles in the rehabilitation and transition process of the participants of this study. Speaking with this group of individuals about physical activity and spinal cord injury may provide new interventionist and outsider perspectives (Peters, 1996).
3. My study was specifically targeted at youth with spinal cord injuries who were interested in physical activity. As identified in past research, as little as 10% of people with disabilities participate in enough physical activity to receive measurable benefits from their participation (Rimmer, 2005). Through further research, I believe there is an opportunity to explore the opinions and lived experiences (van Manen, 1997) of the other 90% of people with disabilities who are not physically active enough to receive measureable benefits from participation following transition from rehabilitation to community.

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APPENDIX A: Ethics Certificate



**UNIVERSITY OF SASKATCHEWAN
BEHAVIOURAL RESEARCH ETHICS BOARD**

<https://www.usask.ca/research/ethics.shtml>

NAME: Donna Goodwin
College of Kinesiology

BSC#: 03-1314

DATE: November 25, 2003

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the Application for Ethics Approval for your study "Illness to Wellness: Building Health Capacity for Youth With Spinal Cord Injuries" (03-1314).

1. Your study has been APPROVED.
2. Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Committee consideration in advance of its implementation.
3. The term of this approval is for 5 years.
4. This approval is valid for five years on the condition that a status report form is submitted annually to the Chair of the Committee. This certificate will automatically be invalidated if a status report form is not received within one month of the anniversary date. Please refer to the website for further instructions: <http://www.usask.ca/research/behavrsc.shtml>

I wish you a successful and informative study.

Dr. David Hay, Acting Chair
University of Saskatchewan
Behavioural Research Ethics Board

DH/ck

Office of Research Services, University of Saskatchewan
Room 1607, 110 Gymnasium Place, Box 5000 RPO University, Saskatoon SK S7N 4J8 CANADA
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APPENDIX B: Participant Consent Form

UNIVERSITY OF SASKATCHEWAN

Informed Consent Form

Title of Study: **The Experience of Transitioning from Rehabilitation to a Physically Active Lifestyle Following a Spinal Cord Injury**

Researchers: Paul Gustafson
College of Kinesiology
University of Saskatchewan
Saskatoon, SK. S7N 5C2
Phone: (306) 955-6512

Supervisor: Dr. Donna Goodwin
College of Kinesiology
University of Saskatchewan
Saskatoon, SK. S7N 5C2
Phone: (306) 966-1073

Purpose and Objectives of the Study:

I understand the purpose of this qualitative study is to describe the experience of physical activity for young adults with spinal cord injuries during the transition from rehabilitation to community involvement. The objectives of the research are to (1) describe the meaning young adults who have sustained spinal cord injuries give to physical activity early in rehabilitation, prior to returning to the community, and after they have returned home, and (2) give voice to young adults with spinal cord injuries regarding rehabilitation practices and the transition to community based physical activity.

Possible Benefits:

I understand that the information I am providing may assist with the development of creative and innovative recreation and leisure opportunities for people with spinal cord injuries, enabling a smooth and positive transition from the rehabilitation setting back into the community.

Procedure:

The study will consist of 3 one-on-one in depth interviews that will last no longer than 1½ hours. I will also be asked to read the transcript of my interview to confirm the accurateness of what was said. This will take approximately ½ hour for a total of a 5 hour time commitment. I will receive a copy of my transcribed interview and will be asked to confirm that this transcription is an accurate portrayal of my interview. I will also have the opportunity to request a copy of any published material produced from this study.

The interview will be audio taped and then transcribed (written out). The researchers may also be writing memo notes during the interview. The research team will be the only people who have access to the audio tape, transcribed interview and memo notes. All audio and documented records will be kept confidential and stored in a secure locked office.

I have been invited to bring an artefact (e.g., photographs, documents, and memorabilia) that represents my rehabilitation and physical activity experiences. The artefacts will be photographed at the time of the interview and returned to me. Under no circumstances will the photographs we used for financial gain.

Risks:

I will not be asked to perform any physical tasks and there are no psychological risks. If at any time I feel uncomfortable during the interview with any of the questions I have the right to refuse to answer and the discussion will be redirected.

In the event that I experience discomfort due to the interview process or would like to discuss issues raised in the interview further, I will put you in touch with the counseling services available through the Physical Medicine and Rehabilitation Unit of the Saskatoon City Hospital.

Right to Withdraw:

I understand that my participation in this study is completely voluntary. I may withdraw from the study for any reason, at any time, without penalty of any sort without losing access to relevant services provided by the hospital. Should I decide to withdraw from the project; my information will be deleted (erased) from the study and paper copies of the interviews destroyed.

If the researchers feel that my participation in this study is causing unnecessary stress on me, I may be asked to discontinue at which time any data relating to the study pertaining to me will be destroyed.

Confidentiality:

I understand that any information I provide (audio recordings, demographic information, and personal information) will be kept confidential. The only individuals that will have access to this information will be the research team involved with this study. Any published or presented material from this study will not disclose any of my personal information. All research material related to this study will be securely stored in Dr. Donna Goodwin's office at the University of Saskatchewan for a period of five years following the study.

Presentation of Material:

I understand that the information I provide for this study will be included in Paul Gustafson's final manuscript for a Master's Thesis. This research document may be submitted for publication in a scholarly journal. Every effort will be made to disguise my identity in all presented material related to this study (i.e. false names).

Research Personal:

If I have any questions regarding my rights or my participation in this study or any other questions regarding this study I may contact Paul Gustafson at (306) 955-6512 or any of the other researchers listed on the front of this consent form. I understand that this research project has been reviewed and approved on the ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board on October 6, 2003.

The study and this consent form have been explained to me and I have been given the opportunity to ask any questions or voice any concerns I may have regarding this study. I have received a copy of this consent form for my files and willingly agree to participate in this research study.

Consent to Participate:

I have read and understood the description provided above; I have been provided with an opportunity to ask questions and my questions have been answered satisfactorily. I consent to participate in the study described above, understanding that I may withdraw this consent at any

time. A copy of this consent form has been given to me for my records.

(Signature of Participant)

(Date)

(Signature of Researcher)

(Signature of Supervisor)

APPENDIX C: Participant Information Form

How many hours / week? 0-10 11-20 21-30 31-40 40+

Are you currently working? YES ____ NO ____

If YES, where? _____

How many hours / week? 0-10 11-20 21-30 31-40 40+

IV. Rehabilitation

Where did you complete rehab? City: _____ Rehab Centre: _____

How long were you in rehabilitation as an in-patient? _____

Were you in rehabilitation as an out-patient? YES ____ NO ____

If YES, how long? _____

Was physical activity part of your rehabilitation program? YES ____ NO ____

If yes, what physical activities?

V. Physical Activity Interests

What were your physical activity interests prior to your SCI? _____

How often did you participate in physical activity? _____

What are your current physical activity interests? _____

Are you involved in any community or school organizations / groups who provide physical activity opportunities for people with SCI? YES ____ NO ____

If YES, what are they? _____

Who exposed you to physical activity after your SCI?

How often do you currently participate in physical activity now? _____

APPENDIX D: One-on-One Interview Guide

Interview Guide¹

Research Question: To explore the meaning youth with spinal cord injuries give to physical activity experiences during the first two years following injury.

Study Objectives: The objectives of the research are to:

- (1) describe the meaning young adults who have sustained spinal cord injuries give to physical activity early in rehabilitation, prior to returning to the community, and after they have returned home,
- (2) give voice to young adults with spinal cord injuries regarding rehabilitation practices and the transition to community based physical activity.

I want to take you back to your time in rehabilitation. Can you remember:

- the smells – room, food, etc.
- the surroundings & decor – room, ward, therapies, personal decorations, cards, flowers, gifts, etc.
- your clothing
- how you felt – physically, emotionally

Interview 1

1. Describe the rehabilitation experience.

What do you think rehabilitation is? (In-hospital, out-patient, at home)

- your experience on the ward
- your experience in therapies

What did rehabilitation mean for you?

- physically, medically, emotionally

What activities are involved?

What daily physical demands are placed on someone with a spinal cord injury during rehabilitation?

- Can you describe a typical day
 - who you saw
 - what you did
 - hours you spent in rehab

Can you describe the demands placed on someone with a SCI during rehabilitation?

- physical demands / medical demands / emotional demands

2. Can you describe what you think physical activity is?

Was physical activity incorporated into your rehab experience?

Can you tell me how physical activity was incorporated into the rehabilitation experience?

What role did physical activity play in your rehabilitation process?

3. What physical activity experiences are/were experienced during rehabilitation?

What was/is your understanding of physical activity for someone with a spinal cord

¹ The questions will be modified as required to reflect the participant group (youth, parents, rehabilitation team) and the length of time post injury.

injury?

What activities are available/participated in?

Have your perceptions of physical activity for someone with a spinal cord changed and how?

Are there activities that are of particular interest/benefit? Why?

4. Describe the importance of physical independence to people with spinal cord injuries.

Interview 2

5. Describe the preparation required to leave the hospital and return to the community.

What are people told about re-entering the community?

What daily physical demands will/are placed on someone with a spinal cord injury upon returning home?

Describe the importance of physical independence to people with spinal cord injuries in returning home.

What role does physical activity play in perceptions of health and well being?

6. Describe what it is/was like returning to the community.

What things were you well prepared for/less well prepared for?

What were the perceptions of others about what you could/could not do?

How did you feel upon returning home?

What physical/emotional/social experiences did you have?

What are/were your experiences with community based rehabilitation?

APPENDIX E: Focus Group Interview Guide

Focus Group Interview Questions

Research Question: To explore the meaning youth with spinal cord injuries give to physical activity experiences during the first two years following injury.

Study Objectives: The objectives of the research are to:

- (1) describe the meaning young adults who have sustained spinal cord injuries give to physical activity early in rehabilitation, prior to returning to the community, and after they have returned home,
- (2) give voice to young adults with spinal cord injuries regarding rehabilitation practices and the transition to community based physical activity.

1. Now that most of you have had a SCI for 2 years or more, can you tell mean what it means to have a SCI?
 - Medically – being home, follow-up, access to medical services, personal care requirements
 - Physically – physical demands & accessibility – at home, in the community
 - Socially/Emotionally – self, family friends
2. Can you describe P.A. for someone with a SCI?
 - Physical well being & SCI
 - Physical wellness & SCI
3. As someone with a SCI can you describe what P.A means to you?
4. Can you describe your experiences with P.A.?
 - Describe what P.A. has done for you
 - Opportunities - medical
 - Barriers - physical
 - Supports - emotional
 - Access to - social
 - Level of importance - psychosocial
 - Benefits
 - Positive
 - Negative
 - Neutral
5. Support systems?
 - What does that mean for someone with a SCI?
 - Dependant / independent / interdependent
 - What does that mean for you?
 - Dependant / independent / interdependent