Exploration of the Experiences and Perceptions of Spinal Cord Injured People who attend Outdoor Recreation Programmes

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Abstract

Outdoor recreation programmes (ORP) have the potential to assist in the rehabilitation and community reintegration process for individuals recovering from spinal cord injury (SCI). Previous evidence provides support for the use of meaningful recreation, leisure activities, and physical exercise in the maintenance of health and development of self-efficacy, peer support and socialisation, thus assisting individuals with SCI to reintegrate back into their communities. However, there are few studies that evaluate the lived experience of individuals with SCI participating in ORPs and the potential benefits of these programmes. A qualitative study using constructivist grounded theory was chosen to gain an understanding of the personal experiences of individuals with SCI who attend these programmes and the influence the programme had on their lives.

Eight individuals with SCI who attended an ORP were interviewed twice using semi-structured in-depth interviews. The first interview occurred at the beginning of the ORP and the second interview took place approximately three months following completion of the ORP. Interview data were supplemented by field notes from observation of the participants on the ORPs. From the data collected a model was developed to reflect the key themes and concepts that represented the participants’ experiences and perceptions of attending an ORP. Overall, the participants’ experience was positive. The model depicted three stages in the overall gains made from attending an ORP. These included: immediate benefits, secondary consequences and real life consequences. Three key themes emerged as being the immediate benefits: i) ‘Gaining knowledge and skills’, ii) ‘Learning from peers’ and iii) ‘Pushing boundaries’. These immediate benefits contributed to the secondary consequences: iv)
‘Building confidence’ and v) ‘Self discovery’. The secondary consequences enabled the participant to vi) ‘Get out there’ and participate more following completion of the programme, with increased options in life and therefore to vii) ‘Live and reclaim life’. These latter themes are considered to reflect the real life consequences of attending the ORP.

The overall substantive theory that emerged from this study was how attendance at the ORP contributed to the participants with SCI reclaiming and living their lives. The participants indicated they had benefited physically and psychologically from attendance, with the combination of these gains enabling them to engage more actively in social, recreational and vocational pursuits. This resulted in each individual beginning to reclaim or succeeding in reclaiming and living their lives. The participants felt that they now had opportunities and options in their lives.

Clinically the data collected in this study and the theory that emerged from the data will enable funders and providers of rehabilitation services to consider ORP as a beneficial adjunct to the rehabilitation and reintegration of individuals with SCI, especially for those individuals who have struggled to come to terms with their injury and have not successfully reintegrated back into their communities. It also provides a clearer framework for the development and selection of relevant outcome variables in future studies on the therapeutic effectiveness of these programmes.
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Dedication

This thesis is dedicated to Lance, Samuel and Gabriella who have provided endless love, support and encouragement throughout this time.

Samuel and Gabriella, you are my inspiration.
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<tbody>
<tr>
<td>ACC</td>
<td>Accident Compensation Corporation</td>
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<tr>
<td>CHART</td>
<td>Craig Hospital Assessment and Reporting Technique</td>
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<tr>
<td>CHART – SF</td>
<td>Craig Hospital Assessment and Reporting Technique – short form</td>
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<td>MSES</td>
<td>Moorong Self-efficacy Scale</td>
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<td>ORP</td>
<td>Outdoor Recreation Programme</td>
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<td>QOL</td>
<td>Quality of Life</td>
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<td>SCI</td>
<td>Spinal Cord Injury</td>
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<td>SWB</td>
<td>Subjective Wellbeing</td>
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<td>WHOQOL - bref</td>
<td>World Health Organisation Quality of Life Assessment Instrument - bref</td>
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1 Introduction

1.1 Research Aims

The aim of this study was to gain an understanding of the experiences and perceptions of individuals with spinal cord injury (SCI) who participate in an outdoor recreational programme (ORP) in New Zealand and the influence this has had on their lives. A qualitative study using constructivist grounded theory methodology was used to gain an understanding of their personal lived experiences.

1.2 Background to thesis

My interest in this topic arose from my position as a physiotherapist working in the community with individuals who had sustained a SCI. I saw, far too often, individuals sitting at home, in front of the television or computer, not socialising or participating in any recreational or leisure activities outside of the home. Often these individuals would indicate to me that they were not participating in ‘life’ as they had prior to their injury. I started to consider the potential benefits of ORPs after speaking to an acquaintance with a SCI who had just attended an ORP. The enthusiasm expressed for the programme was almost uncontainable. This person had seen changes not only in herself but also in the other participants on the programme. The question that arose was ‘Could ORPs be an important adjunct to the rehabilitation process for these individuals?’

In order to recover from this traumatic life changing event, individuals with SCI usually go through a period of structured rehabilitation of between
three and six months in a specialist inpatient spinal rehabilitation unit, which culminates in their return to their community where they receive further rehabilitation as required. In New Zealand, the Accident Compensation Corporation (ACC) assures that the majority of individuals with SCI will be provided with sufficient resources to be able to return to the community. The purpose of rehabilitation is to facilitate functional recovery and independence, enhance quality of life (QOL) and successfully reintegrate the individual back into their community (Wood-Dauphine et al., 2002; Boschen et al., 2003). Community reintegration has been described as ensuring the individual has the necessary skills and resources to be as independent as possible and to be able to participate in community and social activities of their choice (Boschen et al., 2003; Dijkers, 1998; House et al., 2009). The question I have at the end stage of the rehabilitation process, and linked to the above observations, is ‘have we given these individuals the tools to successfully reintegrate back into their communities and into their lives or have we only given them the tools to survive?’

Spinal Cord Injury

SCI is the medical term used to describe an injury or impairment to the spinal cord and is caused by either a traumatic or non traumatic lesion. SCI affects conduction of sensory and motor signals across the site of the lesion. The International Standards Classification of SCI (Maynard et al., 1997) endorses the use of the American Spinal Injury Association (ASIA) Impairment Scale to assess and record the level of injury. Tetraplegia is described as impairment or loss of motor and/or sensory function in the cervical segments of the spinal cord and results in functional impairment of the arms, trunk, legs and pelvic organs. Paraplegia is described as impairment or loss of motor and/or sensory function in the thoracic, lumbar, or sacral segments of the spinal cord resulting in functional impairment of
the trunk, legs and pelvic organs, depending on level of injury (Maynard et al., 1997).

In the past six years in New Zealand, an average of 77 new SCIs have occurred each year, with a majority of these injuries occurring between the ages of 25 and 65 years (Accident Compensation Corporation, personal communication, May 20, 2010). According to the Spinal Cord Society of New Zealand (n.d.) there are currently 5000 individuals in New Zealand with a SCI, of which 66% are males between the ages of 15 and 45 years and 25% are Maori.

Outdoor Recreation Programmes

ORPs vary in description. For the purposes of this study the programme needed to be at least five days in length and offer outdoor recreation to individuals with SCI. Two organisations in New Zealand offer outdoor recreation programmes; Back-Up New Zealand and Outward Bound New Zealand. Back-Up New Zealand aims to encourage continued participation in physical activity therefore aiding health and wellbeing and assist with the development of skills needed to increase independence and confidence in activities of daily living. Outward Bound New Zealand aims to show people their full potential through outdoor challenge and adventure. Historically the funding of individuals with an injury related SCI to attend these programmes has come from ACC. Although I was unable to obtain any official information regarding the specific funding criteria used by ACC for these clients, anecdotally, from discussion with clients and ORP administrators, it appears that they are funded on a case by case basis. As a result funding becomes difficult to justify when there is little evidence about the effects of such a programme or when ACC is restricted financially.
Little empirical evidence appears to exist relating to the benefits of participation at an ORP for individuals with SCI. Anecdotally however, both SCI participants and authors in the field have reported positive effects of recreation and leisure activities. It is hoped that the results of this study will assist health professionals, individuals with SCI and funders to make informed decisions about the potential benefits of attending such programmes. This study may also inform future research in this area by developing theories regarding key variables for further investigation.

1.3 Structure of Thesis

Chapter 2 expands on the background literature related to this thesis. This is divided into the following sections: Spinal Cord Injury, Quality of Life, Life stories and a meaningful life, Rehabilitation and Community Reintegration, Participation in meaningful recreational and leisure activities, Physical Activity, Health issues and QOL, Social Support, Peer Support, Perceived Self-Efficacy and finally an overview of ORPs.

Chapter 3 outlines the methodology used in this study. This chapter is divided into a number of sections. Initially I will provide the background information to Constructivist Grounded Theory and the relevance it has to this study, followed by Participant Recruitment, Data Collection, Data Analysis and Write Up and Scientific Rigor.

Chapter 4 contains the results of this study. This is divided into a number of sections and includes: Participant characteristics, ORP characteristics and an overview of the results which includes a model, reflecting the key themes and concepts that represent the participants’ experiences and perceptions of attending an ORP. An in-depth description of the results concludes this chapter.
Chapter 5 discusses the key findings of this study. This includes a comparison of the results with the existing literature relating to SCI, QOL and ORPs. This is followed by an overview of the limitations of the study, the clinical implications of the study and suggested directions for future study.

Chapter 6 provides a conclusion of the study.
2 Background to Study

This chapter reviews the background literature relating to SCI and ORPs. Initially I will present literature on SCI, rehabilitation and the concept of QOL. I will then explore the components of rehabilitation and community integration that have the potential to influence QOL and which can be associated to ORPs. This will be followed by a review of the past literature that has examined the possible therapeutic effects of ORPs.

2.1 Spinal Cord Injury

SCI is a traumatic and life changing injury. The injury has been described as resulting in a biographical disruption – “where the structures of everyday life and the forms of knowledge which underpin them are disrupted” (Bury, 1982, p.169). This description of SCI is supported by a number of authors who concur that initially following SCI, everything changes, everything is different and the individual’s ability to participate in meaningful activities is reduced or ceases (Corbin & Strauss, 1987; Duggan & Dijkers, 1999; Hammell, 2004a). Kleiber et al. (1995) described SCI as a “disruption that inevitably occurs to one’s identity and life story” (p. 284).

The following two studies provide some insight into the lives of individuals with SCI. Dickson et al. (2008) carried out a series of in-depth interviews with eight individuals who had sustained a SCI at least two years prior to the study. The aim of the study was to gain an understanding of what it was like to live with a SCI. Interpretive phenomenological analysis was used to analyse the data. The participants described an ongoing loss in personal control, independence and identity. The loss of personal control was centred on a loss of control of their bodies (including body functions, emotions
and movement). The loss of their previous independence extended from an inability to carry out activities of daily living to the loss of spontaneity in their lives, with their reliance on others for support emphasising this. The combination of these two areas of loss resulted in the loss or change of identity. This resulted in reduced self esteem and an inability to define themselves by what they do. A complete loss of identity was in fact identified by only one participant, with the other three experiencing a change in identity. The remaining four felt that their identity has remained unscathed. All of the participants though, noted that at times they had felt insignificant, invisible and inadequate even though their identity had not changed. They attributed some of these feelings to the behaviour and attitudes of others towards them following their injury, due to their lack of understanding about SCI.

In contrast, the participants in the Duggan and Dijkers (1999) study spoke of a life worth living following SCI. This study was carried out through a series of in-depth interviews recording the life stories of 40 individuals to assist in the understanding of QOL. The participants had sustained their injury between six months and 12 years prior to the study. Through interviews, the authors identified the high, low and turning points in the individuals’ lives. As in the above study by Dickson et al. (2008) the participants in this study also talked about loss, but this was considered by participants to be only part of their story. This loss was associated with the loss of one’s independence, hope and association with others and was linked mostly with the early days following their injury. The significant high points were: feeling of elation when they recovered something they thought to be lost forever (e.g. re-establishing connections with their past life and feeling ‘normal’), affirmation that their lives were still important to others (family and friends) and the accomplishment of something important following injury (e.g. finishing university). Turning points were associated with changes in the way
the individual saw themselves in relation to their injury and when they realised that life after SCI has value and meaning.

The above studies highlight that the experience of SCI is individual and varied. The importance of a holistic, person centred approach to rehabilitation, in which each individual is psychologically and physically supported through the changes that occur following SCI is indicated.

2.2 Quality of Life

Quality of life (QOL) is described by Noreau and Shephard (1995) as the “surrogate for wellbeing, happiness and life satisfaction, thus making an individual feel that life is worth living” (p. 227), with many authors considering it to be the ultimate outcome for rehabilitation interventions (Hammell, 2004b; Lee & McCormick, 2004; Manns & Chad, 1999; May & Warren, 2002; Noreau & Shephard, 1995). QOL has been reported to be lower in individuals with SCI compared to the normal population (Duggan & Dijkers, 2001; Hampton & Qin-Hilliard, 2004; Hicks & Martin Ginis, 2008; Lee & McCormick, 2004; Post et al., 1998). In a recent prospective, cross sectional survey, Barker et al. (2009) compared the QOL of individuals with SCI and their able-bodied peers and investigated the relationship between QOL and disability. This sample included a cross section of 270 individuals who had sustained a SCI in the past 60 years. QOL, primary and secondary impairment, activity limitation and participation restriction were measured using five separate tools. Results indicated that individuals with SCI had significantly lower QOL than their non-disabled peers and it was found that the two most important predictors of QOL were secondary impairment and participation (p<0.001). Dijkers (1997) carried out a meta-analysis of studies to quantitatively describe the relationship between subjective QOL of individuals with SCI and impairment, disability and ‘handicap’. A total of 19 sample groups (from 29 papers) met
the inclusion criteria for this review. The authors found that the total sample group reflected the general demographic characteristics of the SCI population. The results of this study indicated that individuals with SCI experienced lower QOL than the average person without a SCI. Looking at the different relationships, the relationship between QOL and impairment was not significant. The relationship between QOL and disability was stronger but not consistent across studies. The relationship between QOL and ‘handicap’ (a category that included family role, occupation, mobility, social integration and social support) was significant (p<0.05) and consistent across the studies, indicating that these factors contributed to the subjective QOL of individuals with SCI.

The metasynthesis of qualitative studies by Hammell (2007) provides a more in-depth description of the factors that contribute to and detract from QOL following SCI. A total of seven papers published between 1993 and 2004, met the inclusion criteria for the review. The key factors found to contribute to QOL were: meaningfulness of relationships (by valuing relationships and realising that others valued them as a person), control over one’s life (consciously taking control), engagement in personally meaningful occupations (by becoming involved in activities that are fulfilling, being able to contribute to others’ lives and by viewing what they can still do in a positive light), development of new values and perspectives (looking at life again and reclassifying what is important to them), reconstruction of the feeling of self worth (feeling they were capable, valued and useful) and attainment of biographical continuity (e.g. feeling like their life was back on track). The key detractors of QOL were: problems with their impaired body (e.g. secondary health issues like pain, fatigue, infections, pressure sores) and the sense of loss (e.g. thinking that the plans or dreams they had for their lives had been destroyed, and then struggling to overcome this). These findings support the outcomes of the study by Krause (1998a) who carried out a large quantitative
study to identify the underlying dimensions of subjective wellbeing (SWB) in SCI. All of the 1032 participants surveyed had sustained their SCI at least two years prior to the study. A revised version of the Life Situation Questionnaire was used to measure SWB, with principal axis factor analysis used to analyse the results. The results indicated that by leading an active, engaging life, individuals with SCI gained a greater sense of wellbeing.

2.3 Life stories and a meaningful life

The ‘rewriting’ of one’s life story, being in control of one’s own life and having purpose and meaning in this life appear to be important in community reintegration and QOL following SCI. In an essay based on a review of the theory and research on occupation and identity, Christiansen (1999) wrote “when we build our identities through occupations, we provide ourselves with the contexts necessary for creating meaningful lives, and life meaning helps us to be well” (p. 547). Purpose in life as a mediator of adjustment was explored by Thompson et al. (2003). A cross-sectional survey of 1391 individuals with SCI was conducted to determine this. Five different measures were used to obtain data and analysed using mediation analysis (i.e. statistical examination of the factors influencing causal relationships between two variables). Results indicated that ‘purpose in life’ has a direct influence on adjustment to life with SCI. It was suggested that by helping the individual find meaning and purpose in life will help with adjustment and QOL. The following two studies indicate how meaningful occupation through leisure and physical activity had enabled individuals to look at their lives, start to recover from their loss and begin to reconstruct their lives. Kleiber et al. (1995) sought to explore the relevance of leisure in the lives of individuals with a SCI. A series of in-depth interviews were conducted with 20 individuals with SCI who had participated in therapeutic recreation programmes and been
discharged in the month prior to being interviewed. The constant comparative method was used to analyse the data collected. The participants in this study indicated that SCI had dramatically disrupted their life stories, which included a loss of ability, disruption to relationships, dependence on others and relapse. Linked to all of these areas of loss was the reduced ability to participate in leisure activities. The authors linked the importance and significance of leisure to one’s identity and suggested that through the reconstruction of one's leisure activities the individual may be able to re-establish and reconstruct their life story and thus was an important component of the rehabilitation process.

In a small qualitative study, Levins et al. (2004) explored the experience of physical activity involvement in eight individuals with SCI, using semi-structured ethnographic interviews. A dominant theme that emerged from the data was that of ‘individual influences’. The participants indicated that following their injury they felt they had lost their identity and the way they had perceived themselves had been ‘shattered’. This loss was attributed to not being able to do the activities that were of importance to them prior to their injury. As a consequence the participants indicated that they went through a process of rediscovery and redefining themselves. This process was often difficult as their former identity had been linked with physical activity. The turning point of this process was the point in time when the individuals themselves realised they needed to change, with participants noting that physical activity promoted the change and assisted them in redefining themselves. In a sense they were re-writing their life stories.

Thus, it would appear that adjustment and QOL following SCI are dependent in part on individuals with SCI reconstructing the way they view themselves, reconstructing their sense of identity as a person with a disability and finding meaning in a number of areas of their life. It would appear that
these components should be considered when planning the rehabilitation of each individual with SCI.

2.4 Rehabilitation and Community Reintegration

The purpose of rehabilitation following SCI is most often described as being to facilitate functional recovery and independence, enhance QOL and the successful reintegration of the individual back into their community (Boschen et al., 2003; Wood-Dauphinée et al., 2002). According to Kennedy et al. (2003) and Boschen et al. (2003) rehabilitation should be a dynamic process, assessing the individual on skills appropriate to their functional capabilities and personal goals and thus assisting them to be fully integrated back into their community. Hammell (2004b) explored the perceptions of 15 individuals in regard to their QOL, using semi-structured interviews. All of the participants had a high level SCI and had lived with their injury between four and 28 years. All of the participants acknowledged that they had gone through a period of feeling helpless and useless but at the time of the study they were all glad to be alive and reported a good QOL. From these interviews Hammell (2004b) concluded that for rehabilitation to be effective, it must have a biographical orientation and must “assist each individual in achieving control of his or her life, facilitate the exploration of options and opportunities, encourage the involvement of special people and enable each individual to find something meaningful to ‘do’, such that life is filled with both purpose and meaning” (p. 617). These findings are supported by the Barker et al. (2009) study who concluded that to optimise QOL; rehabilitation should focus on enabling participation as well as reducing secondary impairments and teaching functional skills.

The concept that rehabilitation should be individualised is cited often. In a qualitative study by Carpenter (1994), exploring individual perceptions of their experience with SCI, the participants indicated that each injury is a
personal experience and rehabilitation should be individualised to suit each individual’s needs. This can be achieved by gaining an understanding of the individual and focusing on the individual's specific needs, aims and goals (Krause, 1998b; van de Ven et al., 2005). A number of other studies emphasised the importance of providing the individual with the opportunity to talk about their life prior to their injury, including their interests and to look into how these and other current meaningful activities could be included in the rehabilitation (Duggan & Dijkers, 1999; Tasiemski et al., 2005, 2006).

Community reintegration is described by a number of authors as ensuring the individual has the necessary skills and resources to be as independent as possible and to be able to participate in community and social activities of their choice (Boschen et al., 2003; Dijkers, 1998; House et al., 2009).

A qualitative study by van de Ven et al. (2005) provides some insight into how individuals with disabilities view successful community reintegration. Two groups of individuals were interviewed: i) 11 individuals with a disability (without SCI) and ii) 22 non-disabled individuals socially connected to the individuals in the first group. From the data, a model of integration, including the influencing factors of integration was created. Four prominent people from the disability movement were used to refine this model. From the data, the participants felt they had reintegrated into their community when they were able to function normally without special attention, when they were able to mix with others without being ignored, when they could take part and contribute to society and when they were able to realise their own potential and were the director of their own life. This reintegration occurred by interacting with others in society and was influenced by the attitudes of the individual, the support system provided and the attitudes of society.

Successful reintegration is facilitated by preparing each individual physically and psychologically and ensuring support is in place for the
transition back into their community (Suddick and O’Neil, 2009; Dattilo et al., 1998; Boschen, 2003). The following studies illustrate how participants felt that their reintegration had been hampered when their individual physical, psychological and support needs had not been considered. Suddick and O’Neil (2009) carried out a small exploratory qualitative study, involving seven SCI participants, who were between five and twelve years post injury. The aim of the study was to explore their experiences of reintegration and the influence rehabilitation has on this reintegration. A phenomenological approach was used to gather and analyse the data. The participants indicated that although the inpatient rehabilitation period had provided them some useful physical skills and knowledge, it did not focus enough on participation and community reintegration. They did not feel like they had been prepared enough psychologically or physically for this transition and found there to be a lack of services and facilities available to them when they returned home.

The need for continued support is again highlighted in another qualitative study by Dattilo et al. (1998). The aim of the study was to examine the relevance of leisure and social relationships to community integration. Fourteen individuals with SCI were interviewed between one and eight months following return to their community. The constant comparative method was used for data analysis. The participants indicated that although they had integrated back into their communities to different degrees, they also indicated that a number of factors limited their ability to participate in leisure activities. These included a lack of support, companionship, transport, physical ability and physical accessibility. Some of the participants reported that the lack of opportunities and reduced amount of support following discharge from the rehabilitation unit was disconcerting.
Similarly, Boschen (2003) carried out a mixed method study to examine reintegration and QOL in individuals with SCI. One hundred, self-selected individuals were interviewed for the quantitative portion of the study. This involved the participants completing three questionnaires in order to ascertain the success of community integration through their level of productivity, satisfaction with performing daily activities, satisfaction with community integration and subjective level of QOL. The qualitative portion of the study involved interviewing 34 participants from the first group. Focus group discussions were recorded, systematically reviewed and themes identified using inductive analysis. The combined results indicated that the following factors helped to facilitate adjustment following SCI and reintegration. These include locus of control, social support, health and pain management, individualised rehabilitation and post rehabilitation services, enabling the individual to rebuild their lives and reframe their goal.

Lysack et al. (2007) explored the relationship between perceived environmental barriers and perceived community integration in 136 adults who had lived with a SCI for an average of 11.5 years. The results of this study were drawn from two studies that were ongoing at the time. Although a cross-sectional study design was used in both of the contributing studies, the findings of this study were based on the outcomes from the two quantitative measures used; the Craig Hospital Inventory of Environmental Factors-Short Form instrument and the Community Integration Measure. Results relevant to this current study indicated that successful community integration is challenged when individuals cannot find anything meaningful, productive or fun to do in their communities and when they do not like where they live.

Effective rehabilitation can therefore contribute to successful community reintegration and improved QOL provided attention is paid to developing skills and support that individuals with SCI will need in their lives in the community.
Drawing from the literature above, meaningful recreation and leisure activities, physical activity, social and peer support appear to contribute positively to this process.

2.5 Participation in meaningful recreational and leisure activities

As noted above, having a meaningful life enhances QOL. Therefore participation in meaningful recreational and leisure activities should facilitate QOL and community reintegration.

Many individuals with SCI were young, adventurous and led physically active lives prior to their injury (Kennedy & Smith, 1990; Levins et al., 2004). Of concern then, is the fact that participation in recreation and exercise has been found to reduce following SCI (Brown et al., 2002; Tasiemski et al., 2006), with this population group identified as being amongst one of the most inactive population groups in society (Martin Ginis & Hicks, 2005), spending more time pursuing sedentary activities than they had prior to their injury (Beringer, 2004; Tasiemski et al., 2006). Despite this, leisure activities have been identified as the part of life that individuals missed the most, had lost or were not happy with following their SCI (Kennedy et al., 2006; Kinney & Coyle, 1992; Kleiber et al., 1995). Unfortunately, Coyle et al. (1994) found that leisure is often not prioritised in rehabilitation.

A number of authors have linked QOL and adjustment with active participation in and satisfaction with leisure activities (Carpenter et al., 2007; Coyle et al., 1993; Coyle et al., 1994; Daniel & Manigandan, 2005; Krause, 1998a). In a quantitative study, Lee and McCormick (2004) explored the variables of leisure that may contribute to SWB in individuals with SCI. The sample included 206 participants, recruited via the local rehabilitation centre. The results indicated that four variables were significant predictors of SWB,
explaining 53% of the variance when predicting SWB. The most influential variable was frequency of recreational participation (p<0.001).

A number of studies have shown that individuals with both SCI and other disabilities benefit physically, psychologically and socially from participating in recreational and leisure activities (Lyons, 1993; O'Brien, 2008; Slater & Meade, 2004). Slater and Meade (2004) carried out a critical review of the current literature relating to participation in recreation and sport by individuals with SCI. It was concluded that recreation and sport following SCI provided physiological and psychological benefits and promoted community reintegration and it was recommended that these activities be encouraged during rehabilitation. The authors noted that although a number of previous studies had retrospectively measured the benefits of participation in sport and recreation, they recommended that the psychological benefits of self confidence, self esteem and QOL needed to be explored prospectively in order to compare the before and after participation effects.

Bline and McClung (1997) interviewed 23 individuals with physical disabilities to explore the impact of participation in recreational activities had on their perception of their physical and social self. The participants indicated that recreation and sports had positively influenced their physical self perceptions, increased their confidence to pursue new activities, allowed them to experience their bodies in new ways and had therefore enabled them to redefine their physical capabilities. These findings are supported by Coyle et al. (1994) who examined the life satisfaction of 91 individuals with SCI through structured interviews measuring depression, self-esteem and satisfaction in life, leisure, family, socioeconomic and health status. Using content analysis, it was found that participation in leisure activities had allowed the individual to experience their body in new ways, enhanced their perception of their physical attributes, redefined their physical capabilities and increased their confidence. Socially it had expanded their social interactions and experiences
and resulted in the initiation of new social activities. Loy et al. (2003) carried out a survey on 178 SCI participants to examine the relationship between leisure and SCI adjustment. It was found that leisure engagement was positively associated with adjustment to SCI and emphasised the importance of leisure in the reintegration of individuals following their discharge from hospital. They also found social support was promoted through leisure, which was a positive factor in the adjustment to SCI.

It is important therefore, to know what it is about recreation and leisure that helps with community reintegration and adds to QOL. The following studies propose that the learning of skills, continuity and providing a range of recreational and leisure options all contribute. Kinney and Coyle (1992) suggested that a portion of the individuals rehabilitation should be spent exploring how the disability had impacted on their ability to participate in leisure and follow this up with teaching the individual the necessary skills required to continue or begin leisure activities again. Lee et al. (1996) looked at how individuals with SCI perceived their return to leisure activities in the early stage of adjustment, using participant observation and semi-structured interviews. Twenty participants were interviewed and the data were analysed using the constant comparative method. The authors found that continuity of recreational activities was important. The participants sought continuity in order to reconnect with their past self; it provided encouragement to the individual and a buffer to the dramatic changes they had experienced. The participants who sought continuity, often chose activities they had previously enjoyed, were prepared to accommodate the continuity by adapting equipment, using resources and by adjusting to functional loss. The perceived similarity between former activities and current activities was found to be important for continuity; providing the individual with a connection between their past, present and future. The authors suggested that
reclaiming former activities and seeking continuity is healthy and is part of the process of recovery.

Continuity of recreational and leisure activities can be facilitated by providing options and taking into account each individual and their specific needs. This was demonstrated in the following studies. Tasiemski et al. (2006) examined the continuity of recreational engagement in 985 individuals with SCI. A mixed method research design was used, with the quantitative data collected from a questionnaire designed and previously piloted by the authors and the qualitative data collected from a single open question. Results indicated that the individuals, who continued to be physically and socially active, were younger at the time of their injury, had lived with their injury for less number of years, were more likely to have paraplegia and required less support. Only 30% of the participants in this study continued with pre-injury activities, with participation being dramatically reduced for some of the participants. From these results Tasiemski et al. (2006) concluded that rehabilitation professionals needed to be aware of recreational and leisure activities available to individuals with SCI, taking note of each individual’s past and current interests, with the provision of support to encourage continuation being an important part of rehabilitation. They felt that individuals should be provided with opportunities to become involved in recreation early in the rehabilitation process as this was important in developing their perceptions of post-injury involvement. Although the need to recognise the individuals’ past interests is indicated, O’Brien et al. (2008) carried out a qualitative study to investigate the post-injury leisure participation. Eighteen individuals with SCI were chosen through purposeful sampling in order to include a variety of demographic groups and were selected from a larger study also being undertaken. In-depth semi-structured interviews were analysed using grounded theory. All of the participants agreed that leisure was important (for emotional, interpersonal and physical
reasons) and indicated that they had chosen one or more of the following three routes to enable this participation. These routes were: i) resuming pre-injury activities or continuing pre-injury activities with adaptations, ii) choosing a new activity as a substitute for pre-injury activity or iii) choosing a new activity which was unrelated to pre-injury activity.

As noted above, the inclusion of recreation and leisure during the rehabilitation period appears to promote participation once they returned home. In a qualitative study Caldwell et al. (1994) explored the perceptions of therapeutic recreation during rehabilitation of individuals with SCI. The participants indicated that recreation during rehabilitation provided hope and a sense of future possibilities, information, education and adaptive resources, helped with skill development, provided encouragement, motivation, confidence, fun, enjoyment and diversion, assisting with coping and adjustment to injury, and facilitated community integration. This is supported by Dattilo et al. (1998) who carried out in-depth interviews on individuals who had recently sustained a SCI. The participants reported that therapeutic recreation assisted in identifying possibilities for themselves and raised expectations about what they could do in the community.

The above studies indicate that recreation and leisure activities are important and relevant in the lives of many individuals with SCI and suggest that these activities should be introduced during rehabilitation and that the continuation of recreational pursuits should be planned for and supported once the individual returns to the community.

2.6 Physical Activity

Exercise and physical activity have been identified as important in the maintenance of health, function, improved community integration and QOL
(Krause, 1998b; Manns & Chad, 1999; McVeigh et al. 2009; Stevens et al., 2008; Tawashy et al., 2009:). Unfortunately SCI leaves the individual relatively sedentary, with research signifying that individuals with a SCI tend to exercise less, have reduced confidence and self-efficacy compared to able-bodied individuals (Beringer, 2004; Dattilo et al., 1998; Lyons, 1993; Wise & Hale, 1999).

As a result of the reduced activity, metabolic changes and denervation caused by SCI, a number of secondary health conditions can develop. These include cardiovascular disease, obesity, osteoporosis, urinary tract infections, skin lesions, diabetes and hypertension (Hicks & Martin Ginis, 2008; Mobily, 2009; Vissers, 2008; Yekutiel et al., 1989) which all directly or indirectly affect QOL (Vissers, 2008). Nash (2005) examined the literature on multisystem decline and the need for exercise following SCI. Results of this review found that exercise following SCI reduced the risk of multisystem disease in SCI and that regular exercise reduced pain, fatigue, weakness and musculoskeletal decline. It was concluded that prevention of these factors would enhance health and satisfaction with life. Noreau and Shephard (1995) reported that 25% of individuals with paraplegia had inadequate cardiovascular fitness and were only just able to live independently. They felt that if these individuals continued to remain unfit and live sedentary lives, then they would lose their independence, which in turn would affect their QOL.

Functional independence, vital for community reintegration, can be improved by addressing exercise levels and cardiovascular fitness of the individuals (Hicks & Martin Ginis, 2008; Krause, 1998b; Noreau & Shephard, 1995). Devillard et al. (2007) reviewed the literature on the efficiency of exercise training programmes for individuals with SCI. A total of 65 articles were reviewed with findings being in favour of exercise. The review found physical activities (on top of normal daily living activities) had a direct and
positive effect on health, function and QOL. Through training, secondary health conditions were also reduced, with changes seen in cardiorespiratory, cardiovascular, metabolic, skeletal, biomechanical and muscular systems. These changes lead to improvements in functional abilities, independence and QOL. Santiago and Coyle (2004) surveying 170 women with physical disabilities and found a significant inverse relationship between leisure time physical activity and two secondary health conditions, isolation (p<0.045) and physical de-condition (p<0.036). The results indicated the importance of physical activity.

Martin Ginis et al. (2010) carried out a meta-analysis of studies to determine the association between physical activity and SWB of individuals with SCI. Twenty one studies were included in the meta-analysis with the results signifying a positive relationship between the two components. From the studies reviewed, a number of causal mechanisms were hypothesised: i) physical activity may make the individual feel like they have accomplished and mastered something, which promotes a feeling of self worth, self-efficacy and personal control, ii) physical activity may provide opportunities for social interaction which may assist in community integration, which may improve satisfaction with life, and iii) physical activity can increase the production rate of neurotransmitters, which helps to regulate emotion and control depression. Martin Ginis et al. (2010) concluded that further well designed and controlled studies were needed to establish the exact causal relationship however.

Hanson et al. (2001) studied 48 SCI participants to determine whether participation in sport affected the level of community participation as measured by the Craig Handicap Assessment and Reporting Technique (CHART). The participants were divided into two groups, an ‘athlete’ group consisting of 30 participants and a ‘non-athlete’ group consisting of 18 participants. The ‘athlete’ group scored significantly higher (p<0.05) in four of the five subsets of the CHART than the ‘non-athlete’ group, indicating greater
community integration (physical independence, mobility, occupation and social integration). These results implied that sport increases activity level and therefore social integration. The results from this study highlighted the therapeutic importance of sport in rehabilitation of individuals with SCI, with Hanson et al. (2001) suggesting that exposure to sport should begin early on in rehabilitation and that these results eluded that the therapeutic use of sports to prevent loss of social roles and thus increase level of function and quality of life.

A number of other studies have looked at specific components of exercise to provide direction in exercise plans. Regular exercise appears to be the key to gaining the above benefits. In a randomised controlled trial by Martin Ginis et al. (2003) relating exercise to SWB in SCI, it was found that participants who exercised twice a week reported less stress, less pain, decreased depression, improved satisfaction with physical function and improved quality of life. Muraki et al. (2000) examined the psychological benefits of sports activity in individuals with SCI, looking at the type of exercise, the intensity and whether the benefits differed between paraplegics and tetraplegics. Participants included 53 with tetraplegia and 116 with paraplegia who were divided into four groups depending on their frequency of sports activity. Three instruments were used to measure depression, state anxiety, trait anxiety, tension, anger, fatigue, confusion and vigour. The results signified that those participants in the high frequency sports activity group had statistically significant differences in their depression (p<0.01), trait anxiety (p<0.05) and vigour (p<0.01) scores. No significant difference was found between the individuals with paraplegia and tetraplegia or between the different types of sports activity. These psychological benefits increased when the subject exercised more than three times a week.

Although it has been clearly indicated that physical exercise benefits the individual physically, psychologically and socially, adherence to exercise is
difficult to achieve. Hicks et al. (2003) used a randomised controlled trial to examine the benefits of a nine month long exercise training programme for individuals with SCI. The programme consisted of twice weekly, supervised training sessions. Only 11 participants assigned to the exercise group (out of an initial 21) and 12 participants (out of 13) in the control group successfully completed the trial. The ten participants in the exercise group who did not complete the trial withdrew due to illness, transport problems and work issues. At the beginning of the trial there were no significant differences between the groups. Following the programme the participants in the exercise group showed a significant decrease in pain, stress, depression, greater satisfaction with their physical functioning, greater perceived improvements in health and better QOL than their control group \((p<0.05)\). The results, although based on small numbers, indicate the potential benefits of regular exercise.

However, a follow-up study on the seven people who completed the trial in the exercise group, highlighted how difficult it is for people to maintain the level of activity required to sustain these gains (Ditor et al., 2003). The seven selected participants continued exercising twice a week under supervision, but were unaware that their attendance was being monitored. Exercise adherence, perceived QOL, pain and stress were measured. Results indicated that exercise adherence significantly decreased in this follow-up study and the psychological benefits seen after the first study were not maintained. Ditor et al. (2003) suggested that the reduced adherence to exercise and the subsequent reduction in psychological benefits may be due to the participants no longer feeling obliged to participate in an experimental study and being unable to find the motivation to exercise on a regular basis when attendance was left solely to them. The authors concluded that the results of both studies provide a clear indication that continued exercising resulted in improved psychological well-being but adherence to regular exercise needs to be considered.
Martin et al. (2002) used three focus discussion groups to examine motivation to exercise in a population of individuals with SCI and to look at the perceived facilitators and barriers to exercise. The first two groups consisted of four and six participants respectively who were exercising regularly as a result of their involvement in another ongoing study. The third group consisted of five participants who were not part of the ongoing study and who varied in their level of exercise (ranging from being sedentary to exercising on a regular basis). Open ended questions were used to facilitate the discussion at the focus groups. The results indicated that a range of physical, psychological and social gains were made from exercising. The participants indicated that they benefited most physically and psychologically. They indicated that pain, lack of confidence, depression, time and lack of information were barriers to exercising. Facilitators included accessibility, personal trainers and social support.

Kerstin et al. (2006) used semi-structured interviews to identify factors that influence physical activity in 16 individuals with SCI. Using cross-case analysis, four main themes emerged as influencing factors: i) cognitive and behavioural strategies, ii) finding and supporting environmental solutions, iii) exploring motivation post injury, and iv) capturing new frames of reference (e.g. learning to read your body and acquiring new physical strategies). Wu and Williams (2001) looked at pre- and post-injury sports participation patterns in athletes with SCI. They found that the most important facilitator for introducing individuals with a newly acquired SCI to sport was the opportunity to interact with other individuals with disabilities who played the sport.

These findings are supported by Kinne et al. (1999) who looked at the factors that contribute to exercise maintenance in 113 individuals with mobility impairments. Descriptive analysis and logistic regression was used to analyse the data collected in a self administered questionnaire. Attitudinal factors, including exercise self-efficacy and motivation barriers were
significant predictors of exercise maintenance (p<0.0001). From these results, the authors suggested that in order to promote exercise, the individual’s attitude towards exercise needed to be considered and that increased support from both health professionals and their peers and increased opportunities to exercise will promote exercise maintenance. Kennedy et al. (2005) supported the use of sport as a ‘rich’ therapeutic tool and resource in rehabilitation, suggesting early introduction to sport would facilitate acceptance of disability and improve self perception.

2.7 Health issues and QOL

Pain and depression are two health issues that have been shown to effect QOL but also have a relationship with exercise and recreational participation. Coyle et al. (1993) found that their study population of SCI individuals with chronic health problems reported lower satisfaction with life compared to the non-disabled population. Importantly they found that those individuals who had the same or greater involvement in leisure had greater life satisfaction, suggesting the importance of promoting leisure involvement in the lives of individuals with secondary health problems, including pain. They suggested that this can be achieved through leisure education and counselling to assist the individual to achieve an active and balanced life and maintain good health.

In a number of studies, pain was found to be a significant barrier to participation and inhibited activity and choices in life (Boschen et al., 2003; Ditor et al., 2003). Nicholson Perry et al. (2009) explored how pain-related and SCI-related psychological factors contribute to disability and psychological distress in the rehabilitation period following SCI. Forty-seven participants completed the seven questionnaires selected to measure pain, self efficacy, coping, catastrophizing, anxiety, depression and health. Over
76% of the participants reported having pain. Results from this study showed that pain catastrophizing was inversely related to physical function and that pain and SCI self-efficacy both influenced QOL. Tawashy et al. (2009) looked at the association between exercise, pain, fatigue and depression. Forty-nine individuals with chronic SCI participated in this prospective cross-sectional study. Results indicated that higher levels of exercise were related to lower levels of pain and fatigue, but the direction of this relationship could not be established. Higher amounts of mild intensity exercise and an overall increase in activity was related to less depression. Boschen et al. (2003) found that the maintenance of health and pain management was vital for integration back into the community and improved QOL.

Depression was also found to be a health issue following SCI (Coyle et al., 1994; Elliot & Frank, 1996). Fuhrer et al. (1993) carried out a study to gain a better understanding of depression in individuals with SCI. The findings indicated that approximately a third of the 140 participants scored in the statistically significant range for depression compared to the general population, with mobility, social integration and occupation inversely related to the depression scores. These findings are supported by Loy et al. (2003) who found that participation in an activity was negatively correlated with depression symptoms and those participants with a wide range of leisure activities or opportunities did not display depressive symptoms.

Health issues therefore need to be addressed during rehabilitation in order to assist with participation, community integration and QOL. A quantitative study by Zemper et al. (2003) looked at the value of three month wellness programme for individuals with SCI (covering physical activity, nutrition, lifestyle management, prevention of secondary conditions). Once the programme was completed a series of follow-up phone sessions to discuss progress were undertaken. Forty three individuals with SCI were
randomly assigned to either the intervention or control group, with the intervention group participating in the programme. Descriptive statistics were used to analyse the preliminary data, with secondary analysis assessing pre- and post-programme changes. Results indicated a significant improvement in health related self-efficacy (p<0.05), health related behaviours (p<0.05), stress management (p<0.001), perceived stress (p<0.05), physical activity (p<0.001) and fewer reported secondary conditions in the intervention group. Zemper et al. (2003) concluded that the results highlighted the importance of self-efficacy in changing health promotion behaviour and improving quality of life. This improved self-efficacy helps improve confidence in their ability to make changes and maintain these.

2.8 Social Support

Social support and friendships have been found to be other important components in adjustment following SCI (Dattilo et al., 1998; Loy et al., 2003). Noreau and Shephard (1995) reported that individuals with disabilities are often lonely and lack social contact, suggesting that social support is important in facilitating participation, enhancing a feeling of self worth and thus positively influencing QOL. Social support and socialisation were both found to be a motivator to participation (Isaksson et al., 2007; Wickham et al., 2000).

The relationships between social support, participation and QOL are interrelated. A common barrier to participation is a lack of support, yet by participating, individuals are provided with the opportunity to socialise and therefore initiate these interactions (Blinde & McClung, 1997). Kleiber et al. (1995) also talks about how some relationships are shaped, strengthened and maintained through the leisure activity the people share. Hammell (2004b) found close relationships with family and friends contributed to QOL and
assisted the participants in feeling valued. The authors note that it is difficult to separate the positive effects of relationships and the positive effects of activities, as these are often combined, stating “important relationships underpinned the ability to ‘do’ and contributed to the pleasure of ‘doing’” (p. 615). The concept of a key person assisting in the rehabilitation and community reintegration process is emphasised in a number of other studies. In the mixed method study, Boschen et al. (2003) examined the reintegration and QOL of community dwelling individuals with SCI. It was found that support was an important facilitator and often a ‘key’ individual was responsible for facilitating the rehabilitation and reintegration. Likewise, Suddick and O’Neill (2009) interviewed seven individuals with SCI and the attitude and support provided by family and friends emerged as one of the most important factors in community integration. Other factors included restoring independence, regaining life roles, understanding and redefining life with SCI, attitudes of health professionals and adequate preparation for the transition to home with the provision of community services and support.

However, the relationship between participation in leisure activities and quality of social support appears bidirectional. For example, in a quantitative study, Coyle et al. (1993) investigated the relationship between the leisure lifestyle of individuals with SCI and a number of psychosocial variables. It was found that those individuals who maintained their leisure participation had deeper relationships and concluded that recreational programmes designed to facilitate leisure participation and build social support may significantly enhance post-injury quality of life.

2.9 Peer Support

Peer support and the influence of role models were also found to be important facilitators for participation following SCI (Kerstin et al., 2006; Levins
et al., 2004; Slater & Meade, 2004; Wu & Williams, 2001). McAweeney et al. (1996) conducted a qualitative survey in two centres in the United States. The participants with SCI indicated that their peer recreational activities and peer support needs were not being met. They found that individuals with SCI, who are a minority group in society, were often isolated from others similar to themselves and therefore were unable to share their stories and experiences with each other or provide peer support. Duggan and Dijkers (1999) felt that peer support should be encouraged as “clinicians and patients can learn from one another, but patients truly need one another” (p. 187).

Veith et al. (2006) carried out a qualitative study involving telephone interviews with seven individuals with SCI who were part of a hospital based peer mentoring programme. The purpose of the study was to gain an understanding of the peer mentor relationship. A ‘peer mentor’ was described by Veith et al. (2006) as someone who had successfully lived a similar experience and was therefore able to provide counsel and an empathic understanding to the individual in order to assist with adjustment. The participants reported they had gained emotional, informational and appraisal support from their mentors and as a result made practical, emotional and identity gains. They felt they had an increased knowledge of resources, better time management and a more realistic view of the future. They felt less fearful and stressed and had increased hope. Through this relationship the participants indicated they felt able to redefine themselves and did not feel judged in doing so, were more motivated to work and had a renewed appreciation for life.

In a study by House et al. (2009), caregivers of youth with SCI were interviewed to gain their perspective of their child’s rehabilitation. The importance of peer support was highlighted. Peer support was described as where individuals were provided with the opportunity to interact with others who had shared a similar experience. The caregivers felt that two forms of
peer support were important. Firstly, the importance of being able to talk and interact with other youth with SCI, reporting that this was because only they can truly understand what life is like with a SCI and secondly, meeting with adults who have lived with the disability. The caregivers reported that both of these interactions appeared to be motivating to the youth in this study. These findings are supported by Suddick and O’Neill (2009) who recommended the use of experienced patients in the rehabilitation process. They felt these individuals could teach the new patient skills, educate the rehabilitation staff and assist with the transition back into the community.

Boschen et al. (2003) concluded that there is a need for both informal and formal opportunities for individuals to share advice and support with peers, recommending the inclusion of peer mentoring and support programmes in rehabilitation programmes and community services due to their importance in assisting with adjustment and reintegration.

2.10 Perceived Self-Efficacy

Perceived self-efficacy is another important concept cited in the literature relating to successful rehabilitation, reintegration and QOL. Perceived self-efficacy is described by Bandura (1997) as “beliefs in one’s capabilities to organise and execute the courses of action required to produce given attainments” (p.3). Some authors refer to a similar concept of ‘locus of control’ which is described as “The degree that an individual expects that a contingent relationship exists between one’s behaviour (actions) and outcomes (reinforcements)” (Rotter, 1966 in Hans, 2000, p.39). Bandura (1997) states that self-efficacy beliefs are constructed from four main sources of information: i) enactive mastery experience - by carrying out and accomplishing a task, the individual is able to gauge if they are able to achieve the task, ii) vicarious experience - individuals are able to assess their
own capabilities by watching others, iii) verbal persuasion - when significant others express their belief in the individual’s capabilities, and iv) physiological and affective states - enhancing physical status, reducing stress levels and correctly interpreting bodily states.

It has been reported that individuals with SCI lack confidence in their abilities and have lower self-efficacy than the non-disabled population (Middleton et al., 2007; Wise & Hale, 1999). Middleton et al. (2007) used a cross-sectional study with multiple independent measures to explore the relationship between QOL and self-efficacy in individuals with SCI. Over one hundred individuals completed two postal questionnaires at least 12 months following their injury. Results indicated a significant relationship between self-efficacy and QOL (p<0.001), with high self-efficacy related to higher QOL. The participants in the high self-efficacy group only differed in effect size from the population norms in three domains of the QOL measure. These domains were physical functioning, physical role (ability to participate in work or other activity roles) and bodily pain. Middleton et al. (2007) suggested that this may imply that certain factors may act to lower the QOL in individuals with SCI.

Kennedy et al. (2006) carried out a study in four European countries to ascertain the community needs of individuals with SCI. Results from the questionnaires indicated that participants used a ‘fighting spirit’ and acceptance coping strategies to assist with adjustment. The authors linked these strategies to internal control, stating that those with greater internal control had less psychological stress and improved well being.

Boschen et al. (2003) used a mixed methods study to look at long term adjustment and community integration following SCI. One hundred self selected individuals were used in the quantitative component of the study, with 34 of these individuals attending focus groups for the qualitative component. Using multiple regression analysis and data from the qualitative
part of the study, locus of control was found to be predictive of satisfaction with performance of daily activities, satisfaction with community integration and QOL. The authors concluded that locus of control was important to adjustment following SCI and an important component in QOL.

This concept was supported by Blinde and McClung (1997), who noted that by “perceiving greater control in the physical and social areas resulted in higher levels of self-efficacy and greater risk taking or proactive behaviours” (p. 339). These authors commented that the outcomes from meeting people, experiencing new physical sensations and getting out into the community, represent the foundation on which physical and social growth occurs.

The relationship between participation in exercise and self-efficacy appears to be a bidirectional one. By improving self-efficacy the individual becomes more confident, thus increasing their level of exercise and participation, which in turn leads to a further increase in self-efficacy. This relationship results in an increase in QOL (Hicks & Martin Ginis, 2008; Tawashy et al., 2009). This concept was demonstrated by the following studies. Kinne et al. (1999) found that high exercise efficacy and low motivational barriers assisted in exercise participation of individuals with disabilities. The provision of exercise opportunities through increased access and availability of suitable programmes was found to be an important motivator. There appears to be success in programmes designed to address self-efficacy. Rose et al. (2008) looked at the impact on life satisfaction of an eight session forum providing instruction on self-efficacy for 27 individuals with a SCI or disease. Interestingly, self-efficacy in active living increased following the forum, but life satisfaction decreased. The authors related this to the participants increased knowledge about the health related obstacles. They suggest that a longer intervention period may be more beneficial and also scheduling of the programme at different times post injury.
Block et al. (2010) evaluated a health promotion and capacity building programme, ‘Shake-It-Up’, to ascertain the benefits of the programme in a number of areas, including self-efficacy. Thirty five participants completed the programme which included ten full day meetings, over a period of five months. Another nine individuals chose not to participate in the programme and acted as controls. Topics covered included health promotion, independent living topics, accessible activities (physical and recreational) and peer mentoring. The participants were tested using a mixed methods approach. Quantitative measures were used for self-efficacy, with participants being tested four times; at the beginning, on completion of the programme, and at six and twelve month follow-ups. Qualitative semi-structured interviews were used to ascertain life changes. Results indicated that the participants had significant improvement in their self-efficacy scores ($p<0.007$), with these being maintained over time. Alongside this improvement in self-efficacy was the attainment of a number of goals the participants had individually set, increased motivation and feeling empowered to make changes in their lives.

2.11 Outdoor Recreation Programmes

Anecdotally, ORPs appear to contribute to QOL and the overall health and wellbeing in individuals with SCI and other population groups (Beringer, 2004; Johnson et al., 2001). Although there are a number of studies reporting on various aspects of similar programmes, with a variety of different population groups, very few studies exist that have looked specifically at the lived experiences of individuals with SCI who have attended an ORP. An overview of these studies is presented in Table 1 at the end of this section.

Luckner and Nadler (1995) suggested that one of the main purposes of adventure programmes is to assist participants to develop transferable skills and insight which they could then use in their lives after the programme, thus
providing long term benefits from attending the programme. The authors suggest that individuals gained these skills and insight through learning to construct new meanings from new and old experiences through storytelling, with new life stories being created by using the experiences gained at the outdoor programme.

Hattie et al. (1997) carried out a meta-analysis of 96 studies to examine the effectiveness of adventure programmes on areas including self concept, locus of control and leadership in groups of non-disabled individuals. The findings indicated that the programmes had a major impact on the lives of the participants, which was long lasting. The largest effect size was seen in categories linked to the concept of self control. These included independence, confidence, self-efficacy, self understanding, assertiveness, internal locus of control and decision making.

In preparation for this thesis, only three studies could be identified that had reported on the outcomes of ORPs specifically designed for individuals with SCI. Two of these studies evaluated the same programme, but at different times. The programmes evaluated were run by the ‘Back Up Trust’ in the United Kingdom. The aim of this programme was to offer “individuals with SCI the opportunity to participate in a variety of challenging, single- or multi-activity courses under specialist instruction in an integrated, residential environment” (Kennedy et al., 2006, p.92). The first study was a retrospective study (Kennedy et al., 2005) which looked at the benefits of residential activity courses. A ‘self perception scale’, an ‘impact of recreation of course participation tool’ and eight qualitative questions were used to assess the benefits. From the results, participants indicated that participation in the course increased their ability to cope in daily life, that they found SCI did not have to limit their lives, that they learnt asking for help was part of being independent, that they were more capable than they initially thought, and that they realised people would still accept and like them despite their disability.
The authors concluded that this study provided some evidence that sports and recreational activities benefited the individual both psychologically and socially and was a positive rehabilitation tool. However, due to retrospective nature of the study and the low response rate of 38.5% it was difficult to determine whether the results were influenced by the attitudes of the participants or the course itself.

In the second study, Kennedy et al. (2006) interviewed participants pre- and post-programme attendance. Thirty five individuals were interviewed to ascertain their perception of how the programme had impacted on their ability to cope, their involvement in activities, their relationships, their self perception and also other general benefits of participation. Outcomes were measured using the Life Satisfaction Questionnaire, Hospital Anxiety and Depression Scale, Perceived Manageability and Generalised Self-Efficacy Scale. The results of this study showed a significant difference in two areas; life satisfaction ($p<0.016$) and leisure satisfaction ($p<0.007$). The participants also felt less anxious over the period of the programme and had increased self-efficacy following the programme. All of the participants indicated they would recommend the programme to others and reported their attendance on the programme to be positive and empowering. The results of this study added further body to the results of the previous retrospective study.

Finally, Johnson et al. (2001) reported on a community based programme run for children and adolescents with SCI, with the aim of assisting the transition from clinical to community recreation involvement, to teach life skills and address the issues of sedentary lifestyle and social isolation. The sports and conditioning camp was one week’s duration and it concentrated on exposing the eight participants to as many sports as possible. Participants reported that through attendance they were shown things they thought they could not do, were inspired to participate recreationally, had enhanced self esteem and were also provided with the
social benefits of making friends, conversing and problem solving with peers with comparable life situations. Unfortunately the results of this study appear anecdotal, with no evidence of any formal research methodology having been used.

Other studies, using a variety of populations of individuals with different types of disability support the above findings of physical and psychological change following attendance at ORP. Taylor and McGruder (1996) carried out a qualitative study to identify the meaningful components of sea kayaking in people with SCI. Although this study was similar to the studies above in that sea kayaking was a new activity for all three participants interviewed and that it was an outdoor experience, the duration of the trips appeared short (only one day’s duration). However, the participants reported that the programme helped to promote positive physical and psychological changes and they felt they were able “to confront issues of safety, to succeed, to feel competent, to adjust to an excess of leisure time and to redefine life or self” (p.44).

McAvoy et al. (1989) explored the integrated wilderness experiences of both disabled (including SCI) and non-disabled participants. Qualitative (in-depth structured interviews) and quantitative methods were used to collect data on the participants’ experiences. Following the programme, the participants with disabilities reported increased confidence in what they could do at home, increased willingness to take risks, a better understanding of their disability, heightened environmental awareness, a sense of physical strength and knowledge about self pacing. They reported they would attend another course and had recommended it to others. The authors concluded that integrated wilderness adventure programmes had substantial and positive effects on individual personal traits and lifestyles.

McCleary and Chesteen (1990) used two day river trips to look at attitudes of disabled individuals (including SCI) through outdoor adventure.
Questionnaires were used to examine these attitudes. The results from this quantitative study indicated a change in attitude, with the participants perceiving themselves to be more confident and versatile after the trip. They believed they could do more than they had previously thought and better than before. They also found the trip helped them make new friends, experience adventure and excitement, problem solve, make decisions, improve human relations and feel more self assured.

A number of other studies have reported on programmes utilising the outdoors, adventure and recreation. Each programme studied varied in design, aim and population base but all contribute to the knowledge available about ORPs. Zabriskie et al. (2005) examined the perceived outcomes of people with disabilities who participated in either an adapted snow skiing or adapted horse riding programmes, which consisted of a lesson once a week, for three to five weeks. A questionnaire was completed by the participants at the end of the programme and included descriptive questions about involvement in the programme, perceptions of the programme on quality of life and an athletic identity measurement scale. Results showed that the programme had a positive effect on quality of life (overall health, quality of family life and social life). Participants also report that they were good or excellent at the activity at the end of the programme suggesting that this introduction may help them to develop necessary skills to increase their personal activity and participation and therefore avoid inactivity and the negative effects of this.

Kessell et al. (1985) studied a group of adolescents with either a disability (no SCI participants) or who were chronically ill. The programme consisted of a combination of a two week wilderness and urban outward bound experience. The programme was assessed using both quantitative and qualitative measures. Participants and their families were interviewed using a semi-structured interview three times (immediately prior, two weeks
post programme and six months later). Results showed increased personal efficacy, (internal locus of control) with parents describing their children as having increased independence in self care, illness management and increased socialisation outside the family. The parents attributed this to the learning of new skills, change in attitude, as well as themselves learning to decrease control of their child. This study also showed an increased image of body. Parents described their children as being more self-confident and assertive.

Thomas (2004) examined the effect attendance at an outdoor experimental education programme had on adjusting to an acquired brain injury. This programme involved attending a nine day course consisting of a number of challenging outdoor activities, undertaken either individually or in a group. A mixed method approach was used to determine the effect. In this group the results indicated that the programme assisted in the psychosocial adjustment to their injury and restore QOL.

Studies on the essential components of a successful ORP are few. From the literature it would appear that both personal challenge, the outdoors and the opportunity to mix with their peers assists in the success of the ORP. In a review on facilitating the challenge in adventure recreation, Dattilo and Murphy (2001) reported that adventure recreation should focus on involvement of the individual and the provision of a perception of challenge, is essential in successful adventure recreation. The authors felt that ORPs could provide this perception of challenge to individual skill levels and therefore enable the individual to feel challenged at a personal level, be motivated to participate and gain physically, socially and psychologically from the experience.

In a related review by Beringer (2004), anecdotal evidence was presented from individuals who had attended rehabilitation centres offering outdoor pursuits. This evidence suggested that the nature experience and
outdoor pursuits were valued components of SCI rehabilitation, assisting in functional and psycho-emotional adjustment and thus contributed to QOL. It was noted that this was particularly true for those who had been active pre-injury.

The concept of the natural environment and a wilderness experience as being therapeutic is explored by Frumkin (2001). The author cited a number of studies using a variety of population groups who associated the experience with self awareness, a sense of comfort, feeling of renewal and vigour, increased wellbeing, aliveness and energy.

Anderson et al. (1997) studied the effects of an integrated outdoor adventure experience on individuals with and without disabilities. A mixed methods approach was used, with a variety of assessment tools used to measure attitude, relationship development and skill acquisition. The interviews were carried out four to six months following completion, to assess perceptions of the trip experience on QOL. The quantitative results showed the individuals with disabilities who attended the course had a positive influence on their social activity and interpersonal relationships. Qualitatively, five themes emerged from the data regarding personal changes which supported the quantitative results. These included attitude change towards individuals with and without disabilities, friendship development, skill development, personal growth and reflection and lifestyle changes.

ORPs therefore appear to benefit the individual in a number of ways, although the essential components of this success are still largely unknown. It is surmised there is (largely anecdotal) evidence that participation in an ORP may possibility enhance health outcome for individuals with SCI (and other disabilities) such as improved community reintegration and improved QOL. The shorter and less intense programmes show benefits similar to the longer programmes described. What is still not known are the specific
characteristics of the programmes that contribute to these benefits and the longevity of the benefits.
**Table 1: Overview of studies on ORPs**

<table>
<thead>
<tr>
<th>References</th>
<th>Focus of Study</th>
<th>Methodology</th>
<th>Participants</th>
<th>Key Findings</th>
<th>Limitations of Study</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>QUALITATIVE</strong></td>
<td></td>
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<tr>
<td>Johnson et al.</td>
<td>Recreational therapy for SCI adolescents</td>
<td>Not specified</td>
<td>n=8; All with SCI</td>
<td>Anecdotal support for health and wellbeing benefits</td>
<td>Research method not explained; No time frames provided</td>
</tr>
<tr>
<td>(2001)</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Taylor &amp; McGrunder (1996)</td>
<td>Meaningful components of sea kayaking</td>
<td>Qualitative; Ethnographic</td>
<td>n=3; 2 men, 1 woman All with SCI</td>
<td>Psychological, physical and social benefits</td>
<td>Sample size small; Subjects self selected therefore not representative of general SCI population</td>
</tr>
<tr>
<td><strong>MIXED METHOD</strong></td>
<td></td>
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</tr>
<tr>
<td>Anderson et al.</td>
<td>Efficacy of integrated outdoor adventure programmes</td>
<td>Mixed method: Multiple baseline design for quantitative portion; Modified constant comparative method for structured interviews</td>
<td>n=26; 12 with disabilities, 14 without disabilities. No SCI participants</td>
<td>Psychological, physical and social benefits seen in qualitative data; Significant increase in skill acquisition</td>
<td>Small sample size, with all participants volunteering to be a part of the study; Only 17 participants completed whole study.</td>
</tr>
<tr>
<td>(1997)</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Kennedy et al.</td>
<td>Evaluation of Residential Activity course for SCI</td>
<td>Mixed Method: Non-experimental</td>
<td>n=80 All with SCI</td>
<td>Content analysis indicated psychological and social benefits; High frequency scores for positive impact on sense of coping, leisure and recreation activities, social activities and relationships; Significant increase in self perception</td>
<td>Retrospective design may have reduced reliability – time since participating was up to 5 years; Low response rate – only 30%; Self perception scale not fully validated at time of study</td>
</tr>
<tr>
<td>(2005)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kennedy et al.</td>
<td>Sports Activity Course for SCI</td>
<td>Mixed method: Pre-post intervention outcome for quantitative data;</td>
<td>n=35; 30 males, 5 females All with SCI</td>
<td>Thematic analysis indicated psychological and social benefits; Significant difference in life satisfaction, leisure satisfaction, anxiety scores and self-efficacy.</td>
<td>No control group; Long term effects unable to be studied due to high attrition rate.</td>
</tr>
<tr>
<td>Study</td>
<td>Title</td>
<td>Methodology</td>
<td>Sample Size</td>
<td>Findings</td>
<td>Notes</td>
</tr>
<tr>
<td>-------</td>
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<tr>
<td>Kessel et al. (1985)</td>
<td>Health promotion programme evaluation</td>
<td>Mixed Method: Pre-post test data analysis for quantitative; unclear for qualitative</td>
<td>n=37; 23 with chronic illness or disability; 15 able-bodied</td>
<td>Significant increase in internal locus of control and body image Qualitative data indicated increase in socialisation and recreation</td>
<td>Small sample Qualitative data collection and analysis not described</td>
</tr>
<tr>
<td>McAvoy et al. (1989)</td>
<td>Effects of Integrated Wilderness Adventure</td>
<td>Mixed Method: Pre-post test with control group design was used for quantitative data; comparison content analysis for qualitative data</td>
<td>n=121 for quantitative portion; n=40 of the above 121 for qualitative portion included SCI</td>
<td>Qualitative data indicated psychological, physical and social benefits No significant difference in anxiety levels after participation except in longer trip treatment groups</td>
<td>Quantitative measures not sensitive enough to changes</td>
</tr>
<tr>
<td>Thomas (2004)</td>
<td>Adjustment to Acquired Brain Injury following outdoor experimental programme</td>
<td>Mixed method: Statistical comparison with normative data for quantitative data; Thematic analysis for qualitative data</td>
<td>n=14 participants; n=8 non participants in comparison group</td>
<td>Significant increase in QOL measures of experimental group Thematic analysis indicated psychosocial benefits</td>
<td>Self selected participants QOL outcome measure not used on this population group previously</td>
</tr>
<tr>
<td>McCleary and Chesteen (1990)</td>
<td>Changing attitudes of disabled persons through outdoor adventure programmes</td>
<td>Quantitative; pre post statistical comparison</td>
<td>n=17 disabled participants (including SCI) completed both questionnaires</td>
<td>No statistical difference in locus of control or self esteem Observed trend seen in post- test measures compared to pre-test measures indicating approximately half or more of the participants made gains psychologically and socially</td>
<td>Small sample group No statistically significant changes seen</td>
</tr>
<tr>
<td>Zabriskie et al. (2005)</td>
<td>Benefits of community based therapeutic recreation and adaptive sports programmes</td>
<td>Quantitative descriptive analysis</td>
<td>n=129 participants with disabilities, including SCI</td>
<td>Significant positive correlation between QOL and athletic identity</td>
<td>Difficulty ascertaining causality of outcomes due to descriptive and correlational research methods.</td>
</tr>
<tr>
<td>LITERATURE REVIEW</td>
<td></td>
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</tr>
<tr>
<td>Beringer (2004)</td>
<td>SCI rehabilitation and outdoor experiences</td>
<td>Literature review</td>
<td>SCI</td>
<td>Anecdotal support for health and wellbeing benefits</td>
<td>Anecdotal evidence No literature search methods identified</td>
</tr>
<tr>
<td>Hattie et al. (1997)</td>
<td>Adventure education</td>
<td>Meta-analysis</td>
<td>96 studies No SCI</td>
<td>Statistically significant psychological benefits</td>
<td>No SCI or disabled population groups used</td>
</tr>
</tbody>
</table>
2.12 Conclusion

From the literature above it would appear that a SCI is a very individual experience, but that most individuals experience significant life changes and initially their QOL is reduced. Through the re-writing or recreating of their life story, taking control of one’s life, participation in meaningful recreational and leisure activities, physical activity, maintenance of good heath, the development of supportive relationships and improved perceived self-efficacy, it appears that community reintegration occurs and QOL is enhanced.

The aim of the study described in this thesis was to gain an understanding of the thoughts and perceptions of individuals with SCI attending an ORP in New Zealand. ORPs appear to include a number of the facilitators discussed above and thus have the potential to positively influence the lives of individuals with SCI. A qualitative study was chosen to gain an understanding of the personal lived experiences of individuals with SCI who attend these programmes and the influence the programme has had on their lives. Before the efficacy of intensive outdoor recreational programmes for individuals with SCI can be empirically tested, greater understanding of the possible effects of participation in such programmes is required.
3 Method

3.1 Introduction

The aim of this study was to explore the experiences and perceptions of individuals with SCI who have attended an ORP. Constructivist grounded theory was used to investigate these experiences and perceptions. Ethical approval was sought and provided by the Multi-Regional Ethics Committee, New Zealand Ministry of Health prior to the commencement of this study.

This chapter includes and describes the following: i) an overview of the Constructivist Grounded Theory, ii) Participant Recruitment, iii) Data Collection, iv) Data Analysis and Write up of Results and v) Scientific Rigor.

3.2 Constructivist Grounded Theory

Grounded Theory is a form of qualitative research which allows the gathering and analysis of data to occur simultaneously. For example, whilst the data are being gathered, analysis begins with data being coded. This data is then compared to other data collected and compared to categories already formed. This allows the researcher to explore categories in more depth and to follow leads from data already gathered. Thus the final analysis or theories formed are said to be ‘grounded’ in the data (Charmaz, 2006).

Grounded Theory first emerged in the 1960’s through the work of sociologists Barney Glaser and Anselm Strauss. This new research process enabled there to be systematic methods for carrying out qualitative
research. It allowed theories about social processes to be developed from qualitative data. Later Strauss joined with Juliet Corbin, creating their version of grounded theory which added an emphasis on verificational methods compared to the earlier emphasis on primarily inductive methods. Glaser did not agree with their version of grounded theory, stating it was a fundamentally different approach. Both approaches are still called ‘grounded theory’ and therefore, there really is no ‘standard’ approach to grounded theory (Charmaz, 2006).

More recently, Kathy Charmaz further developed these historical versions of grounded theory with the development and publication of her texts on a constructivist approach to grounded theory. She published a text book detailing the methods, distinguishing it from previous approaches in grounded theory (Charmaz, 2006). Constructivist grounded theory is based on a belief that the collection and analysis of this data can be an interpretative process and that data, instead of being ‘discovered’ is ‘constructed’ through the interactions between participants and the researcher. Thus, in constructivist grounded theory, you study how and why participants construct meaning and actions in specific situations. The benefit of Charmaz’s approach is that (in comparison to Strauss and Corbin’s approach) it more clearly articulates how a constructivist epistemology can be applied to grounded theory. Philosophically, constructivist grounded theory allows researchers to engage with participants over the subject of inquiry, rather than being merely a silent observer. Constructivist grounded theory also confronts the contradictions of applying post-positivist concepts, such as ‘reliability’ or ‘validity’ to qualitative data. These aspects of constructivist grounded theory fit with my perspective on qualitative research and with my research aims. As the researcher I am automatically a part of the study and cannot separate out my interpretation of the data collected and the subsequent coding of this
material. Constructivist grounded theory recognises this. By using constructivist grounded theory methodology I was able to explore in depth individuals experiences and perceptions of their time spent on the ORP.

3.3 Participant Recruitment

Participants were initially approached through an information letter (Appendix 1) via the provider of the ORP with whom they had enrolled. The participants then indicated to the ORP provider or myself that they were interested in the study and happy for me to contact them. Once the participant had indicated an interest, I contacted them to ascertain whether they fitted the inclusion criteria and to further explain the study and the interview process. Written consent was sought from each participant at the first face-to-face meeting (Appendix 2).

To be included in this study the participants needed to have sustained a spinal cord injury and required a wheelchair for mobility. They had enrolled in ORP, given consent to participate in this study, and spoke English (as that was the language that the interviews were to be conducted in). There were no age criteria. Potential participants were excluded if they had any co-morbidity that might have significantly limited their ability to contribute to an open-ended interview (e.g. severe cognitive or communicative impairment secondary to a brain injury). All potential participants however met the inclusion criteria. No one declined to be involved in the study.

Participants were selected using purposeful sampling to recruit a range of participants with SCI. Purposeful or initial sampling as described by Charmaz (2006) is where you “establish sampling criteria for people, cases, situations, and/or settings before you enter the field” (p.100). This is how the initial participants were selected in this study and enabled the
inclusion of men and women, individuals with different levels of SCI and individuals from different cultural and life backgrounds. It had been anticipated that theoretical sampling be used as the study progressed to select participants specifically to explore emerging themes, categories and theories (Charmaz, 2006). Unfortunately this did not occur due to the cessation of the ORPs due to funding issues during the course of the study. However the data gathered from the participants was detailed and varied, enabling rich, interpretive analysis to occur.

3.4 Data Collection

Data were collected through two semi-structured in-depth interviews. The first interview took place at the beginning of the ORP. The interview was scheduled for a time convenient to the participant and when no other programme activities were occurring. As a result most of the interviews occurred in the evening. Either the participant’s room or another quiet and private room within the accommodation facility was used for each interview. The second interview took place approximately three months after completing the programme. This interview was undertaken at each of the participant’s homes. Each participant had been offered the choice of either having the interview at their home or at another location of their choice.

The structure of the interviews (semi-structured and in-depth) allowed the participants the chance to talk about what was important to them, allowed them to express their views of their perceptions and experiences of the ORP. Interview schedules were used as guidelines for both interviews (Appendix 3 and 4). Initially the interview questions were broadly based around reasons for attending the course, what the participants thought they would get out of the course, level of community and exercise participation prior to attending the course, barriers to participation and general health
status. Demographic information (including age, gender, ethnicity, injury level and type, work situation, and time since injury) was also collected at the first interview. In regard to the description of the injury level, following the first interviews with each of the participants and a subsequent discussion with my primary supervisor, it was decided to categorise this level broadly using the terms: cervical injury, thoracic injury and lumbar injury. This decision was made as the majority of the participants did not know their American Spinal Injury Association (ASIA) classification (a more specific classification) and because this data was not essential to the study.

The interview questions for the three month follow up interviews were aimed at gaining an understanding of the participants individual experience of the programme, their perceptions of the positive and negative aspects of the programme, what had changed in their life since attending the programme, what barriers they faced following the programme when they were out in the community, what goals they had set for the future and how these related to the programme, and how important they viewed the course for others like themselves and why.

The first interviews were approximately 30 minutes long, with the second interviews lasting approximately one hour. Discussion with my research supervisors regarding interview technique assisted in the refining of the interview process and assisted in the construction of questions for subsequent interviews. The interviews were recorded using a digital voice recorder and transcribed verbatim following the interview. Participants were invited to have a support person present at the interviews. Pseudonyms were used to refer to both the participant and any other person referred to in the transcripts of the data. Generic names were used for any other data that may identify the participant (e.g. name of town).
Establishing rapport with the participant, field notes and the constant comparative methods are all integral to the data collection process (Charmaz, 2006). These will now be discussed.

**Rapport**

According to Charmaz (2006), in interpretive qualitative research methods the researcher needs to enter the participant’s world in order to “learn about their views and actions and to try to understand their lives from their perspectives” (p.19). In order to do this successfully the researcher needs to respect the participants and their views. This can be achieved by establishing rapport with them, with this rapport assisting with subsequent interviews and observations.

Rapport was gained with each of the participants through my attendance and participation at the ORP alongside them. I met all of the participants for the first time at the beginning of the programme and spent at least one day on the ORP with all of the eight participants before interviewing them. In this time period I was able to begin to establish rapport through our shared experiences. I attended each of the ORPs for their entirety, participated in all of the activities, shared my thoughts, fears and elation about the various activities and socialised with the participants in the evenings. This enabled me to continue to build rapport and further develop the relationships which assisted at the second interview three months later.

**Field Notes**

As noted above I attended each ORP used in the study, in its entirety and throughout each ORP I was able to spend time with each participant, gaining a more in-depth understanding of their lives. Information was collected on my individual perceptions of each participant’s response to both the physical and psychological challenges of the ORP. I also
documented the development of friendships with the other participants and the interactions between the participants, the instructors and the able-bodied buddies. Details were recorded on events or interactions that I viewed as significant in each of the participant’s experiences. Observation of the programme and informal discussion with the programme leaders was also part of the study and assisted in providing essential background knowledge of the programmes and contributed to the development of theoretical sensitivity. My participation on the course influenced the process of data collection during the interviews, allowing myself and the participants to discuss shared experiences and changing my approach to the interview questions. From these observations and discussions, field notes were also collected. These field notes, combined with the interview data and discussion with my supervisors, assisted in the overall analysis and the construction of the substantive theory.

Constant comparative method

Following the constant comparative method of grounded theory (Charmaz, 2006); the interview schedules were adapted as the study progressed to allow the examination of emerging concepts and themes. Discussion with and feedback from my supervisors assisted with this process. The analysis of data using the constant comparative method is an inductive process in which comparisons are made between data, categories and concepts throughout the study period. This allows for analysis of the data and the emergence of a theory. Using the constant comparative method enabled the analysis of data to occur simultaneously with the collection of the data. Through this process I was able to learn from the data collected and use this information to shape the collection of further data. For example, in my original interview schedule I had not included a question on influence of peers. However this soon emerged in the interviews as an important concept related to the study topic. The
grounded theory method allowed me to explore this theme and begin to ask more specific questions relating to the influence of peers on the experience of the participants. Thus the final analysis and theories formed were 'grounded' in the data.

3.5 Data Analysis and Write Up

All of the data collected were transcribed verbatim and then coded by myself, using Nvivo 8 software to assist with management of the data. A clear research process was developed through the course of this study. This process began with the development of the research question and progressed with the development design of the study, data collection and analysis, ending with the write up of the study. Analysis of the transcripts began at the commencement of the research and findings from early interviews were used to shape the questions for subsequent interviews. Data analysis comprised of finding common themes across the interviews and the use of the participants descriptions to construct a theoretical understanding of their experiences. Initially each transcript was coded line by line to look for initial concepts (open coding) (Charmaz, 2006). As analysis continued, I looked at the relationships between the initial concepts and used a second level of codes which enabled me to describe the initial codes at a more abstract level. Codes used in the first and second level of coding were constantly compared to look for similarities and differences. This is described in more detail above, under ‘constant comparative method’. Extracts from the interviews have been used in the results chapter to illustrate the themes that emerged. See Appendix 5 for the key to the transcriptions conventions used.

The next stage of coding was the formation of theoretical categories. Analytic memo writing and the drawing of diagrams were used to assist
with this higher level of coding and the progression towards forming theoretical categories. As noted above, the field notes I collated over the course of the ORP’s allowed me to reflect back on my own observations, experiences and perceptions of the ORP which contribute to and assisted in my understanding and interpretation of the data. The order of and the relationship between these categories were analysed and examined which resulted in a substantive theory being formed from the data. Once again diagrams were used to assist in this process and were revised several times over the course of the study as more data was added and analysed. Saturation of data occurred towards the end of the interview process with the last participant’s interviews adding rich data but no new themes emerged (Charmaz, 2006). This was achieved by using the constant comparative method of data collection and analysis. I was able to use the information already gathered to shape the interviews with future participants and explore themes that had emerged to see if more information could be gathered.

As noted above, data collection and data analysis occurs simultaneously in grounded theory research. Charmaz (2006) described data collection and analysis in constructivist grounded theory as being “created from shared experiences and relationships with participants and other sources of data” (p.130). This was achieved by initially building rapport with the participants which enabled them to feel comfortable in speaking about their experiences and views. Secondly, at both the first and second interviews I referred back to themes that had previously emerged from other interviews and gained their perspective on these themes. I also asked them about their views on the study topic and gained their views on this which not only added to themes that were emerging but created new themes. By being a fellow participant on the course I was able to experience the ORP as closely as possible to what the participants were
experiencing, understanding though that it was my experience and that I was never going to know what it was exactly like for them.

My research supervisors reviewed all steps in the research process to ensure that my methods were accurate and thus allow others to follow the process. Once each interview was transcribed, they were shared with my primary supervisor, who provided feedback on style and technique. To ensure the authenticity of my codes, peer coding was carried out on over half of the 16 interviews by both supervisors, followed by discussions in supervision sessions. This ensured that the codes and themes emerged from the data rather than being imposed on it. This process also enriched the analysis of the data.

Interpretive qualitative methods allowed me (as the researcher) to form categories from the themes that emerge and to create meaning from these. As already discussed my interpretation was not devoid of my own experiences. The categories and subsequent theories of this thesis were a co-construction of both the participant statements and actions and my interpretation of these. By creating a ‘theory’ from the categories I applied a theoretical interpretation of the data and enabled some significance be given to the experiences and perceptions of the participants and allowed others to gain an understanding.

3.6 Scientific Rigor

A number of authors describe how the scientific rigor can be verified in qualitative studies. For the purposes of this study I will use the rigor strategies outlined by Carpenter and Suto (2008) as specified for grounded theory studies. These strategies include analytic memos, reflexivity and data triangulation.
Analytic Memos

Analytic memos were used throughout the course of this study, the analytic memos were used to assist in tracking my abstract thinking around the data collected, to refine categories and to define the relationships that were beginning to or had developed between the categories. I was able to reflect on emerging ideas and the interpretation of these ideas and include the knowledge I had gained from my observations, discussions and prior reading.

Data Triangulation

Carpenter and Suto (2008) described data triangulation as the “involvement of multiple participants or the use of multiple data quotes to corroborate, elaborate or illuminate an emerging theme or the phenomenon of interest” (p.153). This study included multiple participants and multiple quotes from all participants. In this study eight participants were interviewed twice each. The combination of the data that arose from these 16 interviews and my field notes collated from my own observations, conversations and experiences were used to develop themes, categories and the subsequent theory.

Reflexivity

Reflexivity is described by Charmaz (2006) as the researcher’s scrutiny of his or her research experience, decisions and interpretations. Carpenter and Suto (2008) describe it as an essential strategy which enhances the quality of the research and involves making clear the influence of the researcher has on the topic. Both Charmaz (2006) and Carpenter and Suto (2008) concur that the researcher is an integral part of the research process. Charmaz (2006) spoke of the researcher taking a reflexive stance towards the research process and considering how their theories evolved. She states “constructivism fosters researchers’ reflexivity
about their own interpretations as well as those of their research participants” (p.131).

Being reflexive in this study meant that I needed to be aware of and acknowledge my integral part in the production of the study and its data. Grounded theory is an interpretive process and therefore all theories arising from this study were influenced in some way by me as the primary researcher. Throughout the process of this study I endeavoured to remain open to all the emerging data. As described above the emerging data came from a number of sources including the participants, and my experiences. My experiences were influenced by my participation on the programme, conversations with and observations of the participants. The use of field notes, analytic memos, and reflective journals assisted in the construction of a reflexive account. Through the reflexive approach the researcher needs to delve into their own beliefs and feelings the same way they do with the participants (Carpenter and Suto, 2008). I was also influenced by preconceived ideas and thoughts in relation to SCI and ORP’s. As a physiotherapist I was professionally interested in the process of recovery of individuals following SCI and in the past provided rehabilitation to individuals with SCI in their homes. The influence from these experiences cannot be separated from the production of findings in this study. However attendance on the ORPs and debriefing sessions with my supervisors assisted me to challenge the way I interpreted the data.
4 Results

4.1 Participant Characteristics

Eight participants took part in this study. A description of the participants’ key characteristics is presented in Table 2. To maintain anonymity, participant characteristics have been summarised for the whole group rather than provided for individuals. The participants included seven men and one woman. Ethnicity of the participants varied and included New Zealand European, Maori, Polynesian and European. For the purposes of this study, level of injury was only categorised broadly: the term ‘cervical injury’ was used to refer individuals who had upper limb, trunk and lower limb involvement, ‘thoracic injury’ referred to individuals who had trunk and lower limb involvement, while the term ‘lumbar injury’ was used to refer to individuals who had lower limb involvement only. Seven participants used manual wheelchairs and one participant used a powered wheelchair as their main form of mobility. Seven of the eight participants were very enthusiastic about attending the course, with one being a reluctant attendee who had been encouraged to attend by his ACC case manager.

All participants were enrolled and participated in an ORP in New Zealand. Participants came from two separate ORPs run by the same organisation. One participant had attended previous ORPs and was the team leader on the programme attended during the study, with the remaining participants attending for the first time.
Table 2: Characteristics of participants

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>7 Males, 1 Female</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>5 New Zealand European, 1 Maori, 1 Polynesian, 1 European</td>
</tr>
<tr>
<td>Age</td>
<td>Range: 20-63 Years</td>
</tr>
<tr>
<td>Level of Injury</td>
<td>3 Cervical, 4 Thoracic, 1 Lumbar</td>
</tr>
<tr>
<td>Years since Injury</td>
<td>Range: 1-14 Years</td>
</tr>
<tr>
<td>Marital Status</td>
<td>3 Married, 5 Single</td>
</tr>
<tr>
<td>Employment Status</td>
<td>4 Employed, 1 Unemployed, 2 Students, 1 Semi-retired</td>
</tr>
</tbody>
</table>

4.2 ORP Characteristics

Two organisations in New Zealand provide ORPs of at least five days duration to spinal cord injured individuals who use wheelchairs. Unfortunately, during this study, one of the organisations only had one programme scheduled and the sole potential participant from that programme withdrew at the last minute. Therefore I was only able to interview participants from programmes run by one of the two organisations. I attended and interviewed participants on two separate programmes: one winter and one summer programme. The programmes were similarly structured and consisted of two instructors, five participants (including team leader) and five buddies. The role of the instructors was to provide instruction and supervision for all activities. The role of the team leader was to provide support and guidance to the other participants on the programme, while the buddies, who were able-bodied, were there to provide encouragement and support to the participants as required. The two programmes were based in different locations due to the nature of the activities in each programme. Each ORP included a variety of activities, for
example snow skiing, rafting, kayaking, climbing, bush walking and abseiling. At the beginning of the programme each participant was given a booklet to record their goals and reflections of each day. Each day consisted of participating in one or more outdoor recreational activities. At the end of each day all of the participants met to discuss their highs and lows for that day, and to prepare for the following day.

4.3 Overview of Key Findings

The results of this study will be presented initially as an overview and then in sections determined by the themes that emerged from the data. From the data collected a model was developed to reflect the key themes and concepts that represented the participants’ experiences and perceptions of attending an ORP. Three key themes emerged as being the immediate benefits of the programmes: i) ‘Gaining knowledge and skills’, ii) ‘Learning from peers’ and iii) ‘Pushing boundaries’. These three themes contributed to the secondary consequences represented by the key themes of iv) ‘Building confidence’ and v) ‘Self discovery’. The building of confidence and self discovery ultimately enabled the participant to vi) ‘Get out there’ and participate more following completion of the programme, with increased options in life and therefore to vii) ‘Live and reclaim life’. These latter themes are considered to reflect the real life consequences of attending the ORP. The immediate benefits and secondary consequences were significantly interrelated. For example the key theme ‘Pushing boundaries’ resulted in greater confidence, which then encouraged the participant to continue to gain knowledge and skills and push boundaries further.

Overall the participants were extremely positive about the benefits of attending an ORP following a spinal cord injury. The findings from this
study help articulate why the programmes appeared to be successful for these individual participants and how benefits gained during the programmes were perceived to influence wellbeing and social participation once the participants returned to their communities. In general, the programme appeared to provide a safe yet challenging environment in which the participants could try things out and make personal gains from this experience. Interestingly the results indicated that although several of the participants had some thoughts about what they would like to get out of the course, the majority had initially treated the ORP as an ‘experience’ and prior to attending did not fully know how they might benefit. In fact, it appeared the ORP exceeded their initial expectations.

Following attendance at the ORP the participants appeared to remember what life was like prior to their injury and, although they realised that life was different now, they identified that they wanted to reclaim their life and not have it governed by their injury. They wanted to be more in charge of their lives, to have freedom of choice, to participate more, and to live life to the fullest extent possible. The programme appeared to have allowed them the chance to see what they were capable of. The results indicated that by attending an ORP there was a flow on effect, with participants indicating they had continued to live a ‘different’ life, alluding to the possibility of the participants becoming increasingly efficacious in obtaining the life they want.

A visual representation of the main themes arising from this study and their interpretations is presented in Figure 1.
Figure 1: Experiences and Perceptions of attending an ORP

Immediate Benefits
- Learning from peers
- Pushing boundaries
- Gaining knowledge and skills

Secondary Consequences
- Building confidence
- Self discovery

Real Life Consequences
- Getting out there
- Living & reclaiming
4.4 Immediate Benefits - Learning from Peers

The importance of being able to associate with peers with similar disabilities emerged as a key theme from the participant interviews. The experience of facing similar challenges with individuals who had similar disabilities and learning from these interactions were described as invaluable: important opportunities not available elsewhere. Participants made gains through observation, discussion, sharing of knowledge and skills and through camaraderie with their peers on the course. The subthemes of this key theme were: ‘Peer Support’, ‘Isolation’, ‘Role models’, ‘Comparison and competitiveness’ and ‘Life skills’. These will be discussed separately below.

The ‘Learning from peers’ theme was interrelated with the other two key themes related to immediate benefits: ‘Gaining knowledge and skills’, and ‘Pushing boundaries’. While these three themes were significantly interrelated, for the purposes of clarity it is useful to examine each theme individually. For example, the participants learnt skills and gained knowledge from their peers; this could be discussed in either section but will be discussed under ‘Gaining knowledge and skills’.

In the interviews at the beginning of the programme, five of the eight participants indicated that they had been curious about meeting and speaking with peers, but other than that, these meetings and relationships did not feature as a primary reason for attending the ORP in the first instance:

“Yeah well the course, I thought I get more confidence and more freedom in my life. If get more skill and I have a bit more inkling how other people handle the situation and discussion, talk about those things.” (Harry)

However, in contrast, the significance of interacting with peers was much greater than anticipated. Thus, when this issue was explored further
in the interviews following attendance at the ORP, the participants reported that they had learnt a number of valuable things through these interactions with their peers. These included practical things like how to do physical tasks and what equipment was available, but at a higher conceptual level they also learnt about living life with a disability – that life does go on following such a devastating injury and it can be a fulfilling life. The participants also learnt how to approach psychological challenges from their peers and some developed lasting friendships. All of these factors appeared to contribute to an increase in their confidence physically, psychologically and socially.

**Peer Support**

The importance of a group of individuals, interacting and participating together was important and a positive attribute of the programmes. The set up of the programme contributed to creating a bond between the participants and enabled them to feel relaxed and comfortable enough to contribute. The atmosphere was relaxed and encouraging. The team leader often led the discussion and both the SCI participants and the able-bodied buddies were all expected to join in:

“Yeah, I think it was in the early days it was a bit, ah you get a bit of binding, sort of group because we have good leaders and good at talking and at night discussing what is happening and things like that, so you get a bit of group thing and that gives you more self esteem as well and you feel more that you belong to a sort of club you could say indeed.” (Harry)

By being with peers the participants reported feeling less judged and felt more comfortable talking about things and trying things out without feeling the pressure. The security of the group activities appeared to be a valuable attribute of ORP and seemed to provide some form of protection
to the participant when trying something new. This protection gave them confidence to continue to try and to ask questions:

“Because you get a lot out of other guys in the same situation, you learn um what’s out there and as you grow in confidence um you ask more questions um of you know ones like me who have been in a wheelchair a few more years than they have.” (David)

The importance of being able to associate with others who had a similar injury and therefore had experienced similar things appeared to be vital in learning to live with disability:

“yeah, when they say they know where you are coming from or they know what you are feeling or whatever, then they know as well and it sort of puts you a bit more at ease, they are not lying, it is actually someone else knowing what you are going through rather than someone just saying I know how you feel.” (Fred)

Isolation

From the discussions around the importance of peers, emerged a subtheme of ‘isolation in the community’ and the issues associated with this. Living with a SCI in New Zealand can be very isolating due to the small percentage of people in New Zealand with a SCI and this small number being spread over a large geographical area. A number of the participants indicated that they felt isolated which limited their opportunity to talk and interact with others with similar injuries:

“Yes, because I live in [name of town], a small place and you don’t go much out and I know one person…but she has a completely different life. So I am on my own sort of thing.” (Harry)

Participants anticipated that through attending the programme they would be provided with the opportunity to meet others and learn from this. They wanted to see what others could do in their wheelchairs, and how they live their lives:
“Just pretty much to see what else is available for people in chairs, coming from [name of town] there is sort of not really too many people in the same situation…but there is not many paraplegics or tetras around, so really just to see what was out there and push some boundaries.” (Chris)

The nature of the injury was also reported to contribute to this experience of isolation (e.g. the time it took to do things and physical barriers). All of the participants spoke about the frustration of being wheelchair dependent, the physical barriers related to this, and the time it took to do things. As a result they often felt isolated:

“Yeah, it is you live similar things to what they live and you put up with the same things that they have to and it’s quite, um, refreshing really to feel like I mean it’s quite isolating living with this so it’s quite nice to suddenly be around people that also live it.” (Gabi)

Fred, for example, was initially a reluctant attendee on the ORP. In the following statement he reflects on how the ORP could help others he knows with SCI who had isolated themselves as a result of their fears. He spoke of how attendance would help reduce this apprehension about doing something out of their ‘safety zone’. Although Fred is talking about others, this statement also appears to represent how it had assisted him to face his fears and reduce his isolation:

“Yeah definitely everyone should sort of do it as, it should be actually a compulsory thing because I know, almost everyone else I know around this whole town, around the [name of area] area, they don’t get out, they don’t even go out anywhere, they stay in their houses and everything but I think that is because they are afraid a bit or something.” (Fred)

David realised socialisation was an important part of his wellbeing but that opportunities for socialisation were difficult to establish due to his geographical isolation. He found the programme beneficial as it provided
him with the opportunity to mix with others, reinforced this need and motivated him to address this when he returned home:

“I have been talking a lot with my partner and um that is the big thing that I am missing out on in my life is ah group activities, group sport… I really enjoy myself over that week because of the people contact.”

(David)

**Role model**

The concept of role models appeared to be an important part of the ORP experience. A role model was someone who was able to show others how to do things, but also instilled confidence in others to try things themselves. They could show others how they had broken down barriers to achieve things in their lives. The ‘role model’ position occurred by design and also naturally on the ORPs observed for this study. The following extracts demonstrate how role modeling occurred ‘by design’ as well as a natural consequence of the interactions between the ORP participants. These extracts also highlighted the importance of having participants with similar disabilities on the ORP. If the participants on the course had all had different disabilities it might have been less likely that this role model effect would have occurred.

The role model position occurred by design through the use of a team leader on the programme. The team leader was appointed to this position as they were considered to have the leadership qualities required to motivate and inspire the other participants. David was a team leader on one of the ORPs I attended:

“Show other people what they are capable of or help show other people. I say, ‘you can’t make them, but you can show that hey this is what life is about’.” (David)

The following scenario provides a good example of how the ‘role model’ positions occurred naturally. Chris and Bob were participants on
the same ORP and had similar levels of disability. Chris and Bob built rapport during the week and Chris realised that Bob could manage some of the physical tasks better than he could. As a result he would copy Bob. Simultaneously, Chris also realised that some of the other participants were watching him. This resulted in Chris learning from Bob and then showing others what to do. This role modeling occurred separately to the role modeling that occurred through the team leader:

“I quite enjoyed that because you sort of notice during the week from the start to finish, like how I was sort of learning things off Bob and then sort of passing them on almost. Not like the generational thing, but sort of trying to give Andy more confidence in what he was able to do as well.” (Chris)

Bob realised early on in the week that he could use his knowledge and skills to assist his peers. Through this role modeling, Bob also benefited by being able to contribute to others:

“I definitely really enjoyed that aspect of it and I think and just seeing those other guys’ looks up to me I think that proved that it was important that there are people with similar injuries.” (Bob)

By participating in the programme Bob recognised in himself the attributes of a role model and indicated that he would like to continue to use these skills he had recognised in himself to help others once he returned to his community:

“Oh definitely, definitely umm yeah it was pretty cool. That was one thing that I was kind of hoping to do with my bike umm and the idea is to get out there and get people to see me and umm say ‘hey I want to do that as well’ you know and young people in particular. Umm because I guess it’s one thing that is not around these days is role models for people and especially you know role models for extreme wheelchair sports.” (Bob)
Comparison and competitiveness

The importance of having individuals with similar disabilities on the course was also highlighted in the area of comparison and competitiveness. This usually involved one participant comparing their ability to another and then being determined to do as well or better. It gave the participants an incentive to try harder and therefore get more out of the ORP and possibly carry over into their life once they returned home:

“Yeah I think the more people with that type of spinal injury though it would be better, because you would be trying to push yourself a bit higher than the others.” (Fred)

David had been on a previous ORP and recognised the importance of competition between peers:

“the group atmosphere, it’s the mix as a group, because you have all the different levels, ah, and everyone has got a element of ah competitiveness in them and if they don’t have it they soon get a little bit of it because they think well hey, I want to beat him or mmm he can do that so easy or whatever.” (David)

Fred did not anticipate that he would learn anything from the other participants and initially felt he had no-one to compete against:

“I am different from a lot of other people, just the ways I do things and the way other people do things don’t work for me, some do, some don’t… but being the only one, I know he was the same sort of injury as mine as well but, yeah it is a little bit different I think because he’s been a bit longer.” (Fred)

But then on reflection he did start to compare himself to another participant. He began to realise the importance of peers on the programme and how they could act as motivator and provided him with the incentive to work at achieving his goals:
“Yeah definitely I definitely think I will be better than him…. in 10 years time, or however long it is, I will definitely be doing a lot more.”
(Fred)

Gabi spoke about comparing herself to others to internally gauge how she was progressing in her rehabilitation. She acknowledged that she took a long time to get organised each day and had become reliant on others to help her. The ORP had given her the opportunity to see how others managed and organised their day, which made her realise she could probably do a lot more. As a result she had set herself goals at continuing to do this on her return home:

“Yeah, I mean that was huge for me doing the course cause I didn’t realise a tetraplegic could get up and be ready by 9 o’clock and I struggled to do that.” (Gabi)

**Life skills**

Through observation and conversations, a number of participants found they gained personally from seeing others similar to themselves out there ‘living life’. They felt that in their normal daily life they had little opportunity to do this:

“yeah I guess being surrounded by people going through the same thing that was quite good and just listening to their experiences and hearing how they were dealing with certain things and how you always feel a bit sorry for yourself and you meet people who are much worse off and that always make you get over yourself and move forward. Just seeing those people, even though they were less able than you they were still getting on with it and had a smile on their face and having fun was quite inspiring I thought.” (Gabi)

David had lived with his injury longer than the other participants on the ORP he attended. He reflected on his own experiences of SCI and used this to not only continue to motivate himself but to help the other
participants on the programme. He could see the importance in helping the other participants see that life continues on and that it is worth striving for:

"it is not going to be easy but hey you know you have got two choices curl up and die or live it and live it to the fullest and you will get big rewards if you do you know… I get real big satisfaction out of touching those guys’ lives I suppose in a subtle way without forcing myself on them but being able to say look I have been where you are and I know what’s possible and I know that if you live life to the fullest it is the only way to enjoy it." (David)

The other participants in turn appreciated being given the opportunity to observe their peers, talk to them about their lives and learn from this:

"Yeah, I could see people still living life despite their injuries and stuff. That was good …Yeah seeing some other guys in chairs getting out there and doing things." (Andy)

4.5 Immediate Benefits - Pushing Boundaries

This key theme also emerged as an immediate benefit of attending an ORP. The term ‘Pushing boundaries’ was used to describe situations where the ORP attendees were participating or thinking outside of their usual comfort zone in order to make gains physically and psychologically. This theme consisted of three subthemes: ‘Facing fears’, ‘Reducing barriers’ and ‘Motivation’. It appeared that through participation at the ORP, the participants were able to address these and as a result gain confidence. This increase in confidence enabled them to continue to push boundaries.

Facing fears

Following injury, the participants had tended to live a ‘protected’ life, safe guarding and protecting themselves from the unknown. They worried
about what would happen if they did hurt themselves or got into a situation where they needed help. Some of these fears were a result of events that had occurred previously but generally it was the unknown that restricted them the most:

“Anxieties and fears. It is very easy for someone who has had a life changing accident, as you probably come across; having those safety nets of their home and whatever, it is all because of anxieties and fears of what can happen.” (David)

Following attendance at the ORP, a number of participants acknowledged that unspoken fears and concerns had been addressed. Chris expressed how he challenged himself physically on the ORP and therefore faced some fears which had previously limited how much he went out on his own and how he had previously relied on others to do things for him:

“And it takes that fear away of tipping yourself out of your chair. That was always in the back of my mind, you know I've got to watch what I'm doing because if I fall out of my chair, you know what I mean, but it was 6.30 the first morning, on the footpath out the front of the motel you know. It’s taken that away; there are a lot more things you can do without having that fear in the back of your mind.” (Chris)

The participants felt they were able to challenge themselves on the ORP as they felt they were in a ‘safe’ environment with less risk. The support and encouragement provided by the other participants, the instructors and buddies also facilitated this:

“you are just so fearful after an accident of what’s going to happen…Being able to, I suppose you know, have the opportunity to go OK I'm scared, they say that I can do this, so yeah. It just started to relax me a little bit with my own body.” (David)

By confronting fears and as a result pushing boundaries, participants realised they had a greater range of opportunities in their life. Eric
acknowledged that fear had previously stopped him trying things and now
that he has had the chance to do these things he realised he had more
options. Since attending the ORP, Eric reported he has pushed his
boundaries frequently in a number of areas and had benefited from this:

“Yeah, yeah I thought I’d never be able to do that, but yeah I can
basically do anything…made me want to do things like if I just thought
of it just do it as before I would just freak about it and that’s it…and
just that experience of doing all those activities…um just basically the
same thing I said before, no boundaries.” (Eric)

Although Fred listed a number of reasons at the beginning of the
programme as to why he felt he did not need to be there, he also
acknowledged that he did not do much at home as he tended to be
cconcerned something would go wrong that he might not cope with.
Following the ORP when asked about his experiences, he stated:

“um I think it has just opened your eyes into a lot of things that you
can do a lot more um probably not that you can do it if you wanted to I
guess you could do it, yeah because yeah before that it’s not that you
can’t do it, it is just you worry something is going to happen if you do
it, I think is the biggest thing yeah it opens your mental state of frame
like you can do it yeah.” (Fred)

When Fred reflected on the gains he had personally made, he began to
think about other people he knew with SCI who would also benefit from
attending the programme by being given the opportunity to overcome their
fears:

“they stay in their houses and everything but I think that is because
they are afraid a bit or something…just to give it a go, even if they
don’t do anything, just go there and just be there, at least they are out,
and outside of their comfort area sort of and just it will open
everyone’s eyes up a bit more than being stuck.” (Fred)
Reducing barriers

A number of participants acknowledged that they often limited themselves because of both perceived and real barriers. Some participants talked about limiting what they did because they lacked confidence in themselves or because they were frustrated by the physical barriers (e.g. it is difficult accessing some buildings so now they don’t even try). As a result they did not do as much in the day, did not do as much outside of their homes and overall restricted their lives:

“No, that’s most of it really, the way people look at you. That’s the main thing and just the time it takes to do everything is a lot more.” (Fred)

Gabi had restricted what she did away from home as she did not think she could cope without help in the morning to get ready. Through attendance at the ORP she learnt that she was now able cope without her usual carer support and this gave her the encouragement to continue to do this:

“Yeah it was a big step for me cause it was the first time I had been away by myself um and I didn’t know how I would manage and I was pretty worried about all that stuff but I managed so…that was a big sort of tick in the box for me.” (Gabi)

David used his role as team leader to encourage others to follow his lead. David admitted that while on the ORP he often felt exhausted and had to do things he did not particularly enjoy but knew that he needed to push through these barriers in order to set a good example to the other participants:

“So I might be buggered but I will push through it. Like the walks and the getting wet and cold and camp outs. I hate camp outs but I won’t tell any of them that…they grow, you know, everyone grows on the course. They grow a better person, especially if, I know it’s partly the team leaders job as well, is to get the whole group so tight that they
grow off each other and that no one can say no to an activity. No one can say I’m buggered, I want to quit, because they don’t want to let everyone else down and themselves.” (David)

By reducing barriers, a variety of opportunities became available to the participants allowing them the freedom to do more. Prior to attending the ORP Bob limited himself recreationally to the things he knew how to do and after participating in a variety of activities came away with choices:

“Ummm and then the river rafting, like I didn’t know we were going river rafting, no one told me and I was really scared…and umm yeah but I am so stoked that I did it because I would do it anytime now. I love it and it was something that I’m, you know I’m quite an individual sports person and that’s the sort of group, ahhh sports that I could do with people.” (Bob)

Providing the participants with the opportunity to try things out of their comfort zone helped them to face and overcome future barriers. Andy felt like he could try anything now that his previous fears and barriers had dissipated since attending:

“Just kind of the mental and physical challenges, the barriers. Like there were no barriers kind of thing, like you do what you want to.”
(Andy)

Motivation

Motivation is another important subtheme underpinning the notion of ‘Pushing boundaries’. A number of participants commented that prior to their injury they had been very motivated in their lives and since sustaining their injury had lost this motivation. For example, Fred felt he had been highly motivated prior to his injury and hoped he would regain this motivation in the future:

“I was really motivated before, motivated to do everything, giving it all a go…yeah just the physical sort of side of it, not being so tired and being able to keep on going like I used to. Get up and crack into it and
keep going all day instead of going down, down, down until that's it, just burnt out. But I will, it will take time to get back up there. I slowly am, it's a whole number of things physical, physiological and everything.” (Fred)

Following attendance at the ORP, Fred’s attitude towards life had changed significantly. He had acquired the incentive and motivation to change things in his life now. He had started to think about his future and about the goals he had set. He wanted to achieve these things now or in the near future and not wait. He realised that if he kept waiting for the right time, then possibly nothing would ever happen. Fred linked this increase in motivation to the ORP:

"because if you don’t you are going to get stuck in a void I think I probably um yeah I would of all through winter like drowsy colder days yeah, nah it has definitely made me want to go a bit further faster rather that thinking three years maybe four years down the track it has made me want to do it now. It has pushed me yeah it has definitely helped yep.” (Fred)

David reported that in the year prior to enrolling on the ORP he had lost focus of what was important to him in life. As a result of attending an ORP several years previously and recalling the motivation he had gained and the changes he had made in his life as a result, David hoped that attending another ORP would provide him with this motivation and boost again:

"so my motivations gone a little bit and with experience of doing the courses in the past, I knew that this would kick start me into getting back into a fitter lifestyle, weights, physio, pushing — head space, yeah, it's just you know you get, it's hard to motivate yourself sometimes. That's the good thing about these courses, you've got no choice. You've got no choice on a Backup course, you just have to
get out there and do it. I think it’s the same philosophy with everything, you know.” (David)

As noted earlier it is very difficult to separate the three themes related to immediate benefits of the ORP. The ORP provided the participants the opportunity to observe others on the programme overcoming obstacles and allowed them the chance to talk to others about how they addressed different issues. This enabled the participants to then use this new knowledge and begin to think about how they could begin to do the same, push their own boundaries and as a result start to do more:

“You see other people and how they do it and you talk to other people how they do it and it gives you more ideas and more freedom to do those things.” (Harry)

Whereas, other participants observed others facing fears and gained personally from that:

“From watching others and from the whole group getting so tight and so where that everyone is pushing themselves to the limit and growing through their fears, or pushing themselves through their fears, that you feel so privileged and those endorphins that it gives you. It’s just such a motivator for you.” (David)

The supportive environment at the ORP appeared to provide the participants the opportunity to push themselves without fearing the consequences. Harry was quite capable in his chair and in managing himself but lacked confidence in himself and his abilities. He admitted that he had restricted himself at home as he was afraid of the consequences should something go wrong. Through the support provided on the ORP, Harry felt protected and safe and therefore felt confident enough to start to challenge himself. As he began to realise that he could manage different tasks and activities he started to gain the courage to continue to push his boundaries:
“This course, because I was a long time restricted from, like I couldn’t go out of the house and well it’s all new and I didn’t, I couldn’t do a lot of things what I normally did and so I need a bit of sort of experience and new learning things, and a bit of courage and more courage to do things. “ (Harry)

The security of the group situation with their peers, able-bodied buddies and qualified instructors appeared to provide the participants with the support and encouragement they needed to push themselves:

“I think that is a big part, it is being out in the community, and doing the activities and having that mind shift of oh my god I can’t believe that we have done that um it’s making you feel normal. We are doing normal life stuff um we are not in any protected area we are out in the community doing normal stuff um from scuba diving to rock climbing to abseiling we are all always out in peoples view and I think um that makes the participants feel normal because there is this protected group, they are not individualised and that sets of that confidence and um I suppose it is trying to keep that confidence going once they have left the course but it definitely starts it.” (David)

4.6 Immediate Benefits - Gaining knowledge and skills

This key theme also emerged as an immediate benefit of participating at an ORP. Participants found that by participating in a number of challenging situations with their peers, knowledge and skills related to living with a SCI were gained. These were gained in combination with the other two key themes ‘Learning from peers’ and ‘Pushing boundaries’. The types of knowledge and skills that were gained included: physical skills, recreational and leisure options, equipment and the adaptation of equipment, resources and facilities, and learning about themselves. These will each be described separately below.
Physical Skills

A number of participants identified that they had been active prior to their injury and had not resumed the same level of activity since sustaining their injury. They indicated they wanted to learn the physical skills to enable them to participate:

“I thought this is a good course for giving you a bit more skills and learn, ah to free yourself a bit.” (Harry)

Following attendance participants reported that, through observation of their peers, they not only learnt how others carried out a variety of different physical tasks and activities but also gained the confidence to try different approaches themselves. Chris spoke about learning how to remove his wheel to get through narrow spaces and the confidence he gained from learning this technique. Although he had not had to use this new skill since returning home, he knew he could now get through narrow spaces if necessary:

“I am definitely more confident in my chair and abilities, especially after the bush walk...The taking the wheel off thing, you know with getting in and out of places...yip, I mean I haven’t had to use it again, but knowing that you can—” (Chris)

Through observation and discussion with the participants, the importance of learning physical skills from peers rather than able-bodied others were highlighted. This was purely because of the fact that their peers have experienced life in a wheelchair. Some of these skills could be considered the ‘tricks of the trade’. This idea was highlighted by Harry, who felt he was able to learn more from his peers than he had through his entire inpatient rehabilitation period:

“yeah because you can learn in hospitals how you can transfer and things like that but then if you have other people they have experience and they can show you how they do it and what they do and how they approach things so it is more an inside of a thing of somebody who is
in the same situation and they can better explain than someone who is not in that situation and they approach it more directly.” (Harry)

The following extracts are a good example of how the ORP facilitated the gaining of knowledge and skills. Chris and Bob both independently talked in their interviews about a bush walk they completed together on the ORP. This bush walk was very challenging; a major test of their wheelchair skills. Bob was the more confident of the two and had been happy to lead:

“I think Chris as well to some extent. I mean he was quite an individual person umm but yeah I have a sort of suspicion that he was pretty stoked that I was kind of showing in a way that it is possible.” (Bob)

Chris was more reserved and not as confident in his ability. He looked up to Bob and quietly observed how he tackled obstacles. Following Bob’s lead, he learnt new skills and was successful in putting them to the test by managing to navigate the track:

“Yip definitely, especially Bob. He’s been in a chair longer. Just like pretty much following him through that bush walk, you know, and seeing what he was able to do and then trying it. I think if I was in the front I would have been a bit more reserved as to what I was able to do…Whereas following on, oh well Bob went down there so I can give it a go.” (Chris)

Through my own observation I think that if it had been just one person in a wheelchair attempting the track then they would not have achieved or learnt as much. Some participants had specific goals they wanted to achieve from the course, whereas others did not have any. Bob had snowboarded prior to his injury and had enrolled on the ORP to learn how to ski. He found he had not only learnt those skills but completed the programme with many more skills. He found he had enjoyed a number of the other activities offered (e.g. kayaking) and that he had also enjoyed the group activities, something he had never contemplated as he had always
participated in individual sports prior to his injury. He could see himself participating in these in the future:

“I decided to come on the Backup course to gain some sit ski skills pretty much…I pretty much had it set in my mind why I was doing the course umm it I mean you know, it gave me more that what I expected.” (Bob)

Recreational and leisure options

Hand in hand with learning physical skills, participants indicated that they wanted to learn about what options were available recreationally. They felt that since their injury their options were limited and that life in a wheelchair was restricted:

“Ahhh to tell me about outdoor activities, I was ahhh pre-injury I was a very active young man, ahhh did a lot of, played a lot of sport…umm just being active eh, I missed that and so being on this outdoor programme is definitely umm, yeah.” (Andy)

Following attendance at the ORP, Andy realised he could do a lot more than he had ever anticipated. Throughout the ORP he had participated in and learnt about a variety of recreational activities he could do. He had also learnt how to adapt equipment to enable participation once he returned home:

“Yeah, because since being in a wheelchair I thought there is not much I can do, but since being on the course there are things I can do. There are ways around it and there is always a solution to how to do things.” (Andy)

Participants often felt they were limited in their recreational options because they did not have many opportunities to mix with others similar to themselves. This emphasised the importance of these programmes in providing individuals in wheelchairs the opportunity to gain knowledge and skills in order to provide them with options. By learning new physical skills and being provided with the opportunity to try a variety of activities, the
ORP have provided a greater repertoire of recreational and leisure options to the participant:

“Um well it has probably given me a lot more to go for a lot more too um I guess more to choose from than I originally thought before in some ways yeah.” (Fred)

Harry had felt he was limited to only adapted wheelchair activities, but through participation at the ORP he learnt about other activities and gained the skills and confidence to consider doing these activities back in his community:

“I like rock climbing because you have to use your arms and it was quite safe, because I had to have a sort of safety thing and I didn’t know how it worked but now I know how to do it and I could go rock climbing if I wanted to because I know how to handle it…Ahhh, you learnt skills in that course.” (Harry)

The participants also learnt that through participation they could once again do the things they had enjoyed prior to their injury and with some assistance and adaptation this was possible:

“Um probably getting back into things that I used to enjoy and wasn’t sure if I could do them and it was good to give them a go and know that I could still doing them. I mean things like caving I never thought I could go caving and that was pretty neat, that was probably my favorite activity.” (Gabi)

Equipment

An important part of learning to adapt to living with a disability is having the most suitable equipment. Some participants expressed this as a reason for attending:

“wanted to learn about equipment and gear and stuff like that, that I could use and take from the course and maybe use later…I guess the instructors know a lot about equipment, gear and stuff.” (Gabi)
During the ORP participants were able to discuss equipment issues with their peers and trial each other’s equipment. By learning about equipment from their peers the participants were able to make things easier for themselves and those that assisted them, which enabled them to improve their lives. Following attendance a number of participants identified this as a positive aspect of the course. Participants were happy to share their knowledge about equipment they had found successful to enable their peers to have the same ease of use:

“Yeah I got the website or the brand off Fred’s one. I mean that’s the first thing, I met Fred, rolled into the room and he had his shower chair still all packed up in the bathroom. He saw my [name of relation] bring my one in, you know, even he was struggling with it you know, let alone me. Fred was like, check this one out, you know, straight away just went over and one arm picked it up, sat it on my lap, you know, and then I just watched Fred, took him five minutes probably. He unpacked it, slotted it all together and was away.” (Chris)

Harry reported that he had struggled with his wheelchair for some time and as he lived in a small town, he was unable to compare his wheelchair with others and also felt he did not know enough about wheelchairs to ask for an equipment review. While attending the ORP, Harry was able to do a comparison and realised he needed to make some changes to his wheelchair. Through this knowledge, he gained the confidence to ask for changes to be made. When he returned home he contacted his wheelchair provider and asked for his wheelchair to be reassessed and for changes to be made:

“So they changed that straight away when I came back from the course and they pushed the wheel a bit forward that is what they did, two clicks I think...yeah and so now I can jump easily over the doors that were on the course I found that out.” (Harry)
Another important aspect of learning about equipment was also learning about the modification of recreational equipment which enabled the participants to participate in different leisure and social activities. Participants were often amazed how little needed to be done in order for them to participate and sometimes how no special equipment was required. A good example of this, were the adaptations made to the rafts in order to enable the participants to experience white water rafting. Seats were adapted from plastic garden furniture and secured to the raft to provide the participants with trunk support similar to that of their wheelchairs:

“All the things that were just easy homemade equipment, adapted equipment, you know, because you look at a raft and think, how am I going to sit on that and keep my balance without being literally tied to the raft.” (Chris)

By showing the participant ways of adapting and modifying equipment in order for them to experience challenging and exciting activities, it appeared to have inspired them to continue to do this once they have returned home. Two participants spoke of how they had used this knowledge to begin thinking about how they could adapt equipment at home in order to enable them to participate in recreational activities again:

“There was like a kind of can do attitude. Everything that we did on the course, there was always a creative way around doing things. I enjoyed it, it was really good.” (Andy)

Resources and Facilities
The ORP is held in different venues depending on the season and the activities planned, with each day’s activities held ‘on location’. By experiencing different places with a range of facilities (from no accessibility to full accessibility), participants found they could cope with limited resources and accessibility:

“I loved camping before my injury and I never actually thought, well I kind of thought it may be possible later on. I didn’t think at that stage
of my rehab it would be possible, but it was good to know that it was with a bit of help, um and I managed even though there were no good toilets or shower I managed sort of just bit my lip and got on with it. So yeah, that was a really good experience to know that you can cope in that situation and you have just got to be a bit creative.” (Gabi)

They also discovered that places they never imagined would cater for people with disabilities, actually did. This discovery provided them with the knowledge that accessible facilities exist and even when they don’t, they could cope:

“Yeah well even coming here, like finding out about this place, how accessible it is, is just fantastic.” (Bob)

One participant, Fred, felt that by attending the ORP he had almost completed a trial run of going away from home. This was significant to Fred as prior to his injury he had travelled extensively and spent little time at home. Following his injury and discharge from the rehabilitation unit, Fred had not spent one night away from his home. He had felt he would not manage without all of his equipment (commodes, electric bed and hoist) and full carer support. As a consequence this had restricted his life. The ORP had provided him with the knowledge and skills to now consider this:

“Just basically getting away because since my accident I have gone from hospital to hospital, spinal units to hospitals, and I’ve just sort of, the last year I’ve been at my house and I’ve been there every night. I haven’t been away so this is basically sort of a chance for me to get to know what I need to get away and that, because I will be going away more often, but this is sort of just a chance to see how, instead of going overseas or going wherever I’m going, to see if something’s going to happen it may as well happen here. So it’s a good stepping stone sort of for everything really.” (Fred)
Learning about self

All of the activities on the ORP were physically demanding and each day was busy. Participants were expected to be ready early each morning and participate in all activities. This often reminded the participant of what it had been like to be busy and physically active prior to their injury and has inspired them to return to activity:

“umm, oh since we started this activities, this day’s activities today and I just feel like, umm, yeah, just feel like getting back into, umm, some exercise you know, kind of fitness kind of thing. Cause I used to do a lot of that pre-injury, and umm, it’s one of the things I wanted to get out of this course, some motivation and some confidence and yeah especially some, some activities yeah.” (Andy)

Through participation and becoming more active, the participants also found they felt healthier and enjoyed the benefits of this. Eric found that by becoming more physically active following attendance at the ORP he felt better both physically and mentally and this had resulted in him making some healthy choices in his life:

“yeah you can switch on faster than usual yeah as before I was just real tired all the time...yeah it actually made me give up cigarettes but it had to take two three weeks after the course to realise I don’t actually need cigarettes.” (Eric)

Harry was inspired to continue to be active following attendance at the ORP and found he had more energy. Prior to attending the programme he did not do any regular exercise except for his weights and realised he needed to and that he benefited from this:

“but I reckon I felt very good when doing the course and what I think I got out of it is that I would like to do a bit more exercise with say a bike...and that is good exercise cause now I do only weights but you need stamina in exercise.” (Harry)
The participants also realised they enjoyed being physically challenged and having their boundaries pushed. They gained from being pushed, realising that they would have not done this by themselves and developed because of it:

“I liked it, it was good. It got me out of my comfort zone, yeah I enjoyed it…When I was getting down those steps, that was a big one for me. I never tried it by myself, it was good” (Andy)

4.7 Secondary Consequences - Building Confidence and Self Discovery

It has been demonstrated that by participating in an ORP participants were able to interact with and learn from their peers, gain knowledge and skills and push boundaries. The combination of these three themes appeared to result in the secondary consequences - ‘Building confidence’ and ‘Self discovery’. These two factors seemed to provide the participants with the freedom to think more about their lives, set goals, get out there more and start living and reclaiming their lives.

The need to make changes in their lives, gain confidence and learn about themselves had been expressed by the participants at the beginning of the ORP. Generally they felt they needed to rebuild their confidence physically or psychologically in anticipation that this would enable them to participate more in life. When asked what they wanted to get out of the ORP, comments included:

“Probably confidence in physical activities. Confidence in living with other people, maybe outside of my own environment. Confidence in going away with others as well, which I haven’t done so much yet.” (Gabi)
They wanted to learn more about how to live life with a SCI:

“So you get a bit more of inkling about what’s going on and what it’s about, and it gives you a bit more confidence to do things differently than before.” (Harry)

It was common for participants to report a decrease in how often they got out of the house and socialised following their injury. Participants reported that this was linked to how they felt about themselves and their level of confidence. For example, prior to being on the ORP, Andy had socialised little, although he recognised that when he did go out, he had felt good, but that he had still found it difficult to do:

“I just don’t get out as much as I want to anymore, like uh not very social...It is my confidence and self esteem, really eh, since my injury and, its playing a big part in it—Umm I mean I have good days and bad days yeah. It’s mostly, it’s, mostly bad days but when I, when I actually get out it feels good.” (Andy)

**Building confidence**

The expressed need for increased confidence was translated directly into the actual gaining of confidence following attendance at the ORP. Participants spoke about gaining confidence in a number of areas:

“I suppose, its mainly, it’s going to get people who are quite probably like me just sitting around not doing a lot, it’s going to push them to get them out, out of the house, more confidence, doing things in the community. Maybe going back to work, pushing something like that. Yeah it’s going to get them out with people in similar situations, to, like we said bounce ideas around, build confidence.” (Chris)

Gabi reported that she was able to face some fears, compare herself to her peers and came to the realisation that she was doing well and as a result began to feel more confident about herself:

“Probably that I can give things a go and I need to stop worrying and just try it. Um what else? Um, physically I think for me it was a bit of a
boost I mean I realised that physically I was doing ok and I was pretty
strong and I was managing alright um. Yeah and I guess it just got me
thinking about the future a bit more and what I wanted to do and
where I was going.” (Gabi)

Participants talked about learning they could do more physically than
they had envisaged. Chris’s increase in confidence came with the
knowledge that if he can tackle rough walking tracks in his chair then rolling
around town would never be a significant concern again. Things that had
previously concerned him were minor in comparison to the obstacles he
had faced and overcome on the ORP:

“I am definitely more confident in my chair and abilities; especially
after the bush walk…I mean, you know we were going down wicked,
wicked hills and stuff.” (Chris)

Gabi had never been away from home by herself since her injury, but
by the end of the week had an increase in confidence, which resulted in
her not hesitating to drive home at night instead of waiting until the next day
to drive during the day. She knew she was now capable of this task
mentally and physically:

“That was, I mean that in itself shows how confident how I sort of felt
cause I said ‘no, no I'll just go home’.” (Gabi)

By gaining confidence physically and psychologically, participants felt
more capable in their ability to socialise:

“Sociable, outdoors or activity stuff it is not as bad anymore, it is not
as big as you perceive it to be…what it does is it brings it back down a
little step I guess it is not as big as you think it is going to be.” (Fred)

Participants spoke of having greater confidence in expressing
themselves and becoming more proactive in requesting or gaining ones
needs. Prior to attending the ORP they felt they often relied on others to
make decisions for them, which took away some of their independence.
Following participation on the ORP and through interactions with peers, Gabi felt increased confidence in her ability to direct others when she needed help. In the past she reported that she would have been hesitant to ask for help:

“I knew what to tell them to do and I knew how they needed to help me so that was good.” (Gabi)

Eric realised that he lived in an isolated situation; that his home town lacked opportunities for him and there were few others with similar injuries. He realised he wanted more and almost immediately following completion of the ORP, Eric started to make changes in his life. He gained the confidence to move to another town, which significantly changed his life for the better:

“Lots of reasons, ah just to meet more people in wheel chairs and how they have overcome basically what they had to deal with. Umm sports, study and yeah. Not like up in [name of town] just isolated from everything, no sports provided for you…cause they were wondering why I wanted to move because they have already modified a house at home though aye. Just told them that up in [name of town] there is nothing for me, like social wise, education wise and sports wise and yeah after that got through to them they, yeah starting rolling.” (Eric)

Physical and psychological confidence also enabled the participants to have the courage or confidence to explore recreational and leisure activities which had previously seemed so daunting:

“Because of it is unusual activities, it gives you much more confidence to go out and do things that you think before you couldn’t do and now you think ‘that is not so bad, I can do that’. I think this course, well five days is not that long, but it is quite intensive and a lot of exercise and ah.” (Harry)
By trying out new activities and activities they had done as an able-bodied person and being successful enabled the participants to gain confidence and feel confident to try it again back in their own communities:

“Um probably knowing I can still do some summer activities, I think I sort of wrote summer off because of the wheel chair but now I know I can still do some I just need a hand…yeah it definitely has with my sports and activities.” (Gabi)

Bob felt he had gained confidence through participation on the ORP and on reflection would like to encourage others to attend. He had gained confidence in both his physical ability and in his ability to support and encourage his peers. Through this increase in confidence he now felt confident enough to speak to others in a similar situation and encourage them to attend in order to make the same gains:

“It gives me the confidence to be able to go to someone that may have recently had an accident and say, dude this course is cool you should check it out. I think you would be good at it…Cause I know that they lack kind of confidence and I reckon that the course would instill confidence in them and make them realise that they can do a lot more than what they think.” (Bob)

When participants were assisted to face fears and push boundaries they gained confidence to enable them to feel free, make plans and become more involved in life. The variety and intensity of activities the participants experienced during the programme enabled them to see that they could push themselves, could cope in different and challenging circumstances and survive:

“I think that, I mean you’re always going to be anxious at this stage in my rehab I’m always going to be anxious about new experiences and I think that was so many new experiences thrown into one week and that was really good to know that yes you’re going to worry about it [but] you’ll manage quite good and the only way you’ll know is by
doing so yeah…it's good to know that you will manage it and whatever life throws at you, you just deal with regardless of the situation of where you are or whatever” (Gabi)

Self discovery

By gaining confidence in their ability, both physically and psychologically the participants began to learn more about themselves. They learnt what they were capable of in their new bodies, how to manage life in a wheelchair and through this process gained a stronger, and more positive sense of their identity as a person with a disability:

“Self discovery um and it's all comes back to personal growth and everything like that...It is the start of getting a bit of confidence um I think it is very important.” (David)

Gabi spoke about being born into a ‘new world’, her life with a SCI being foreign to her and something she had never thought about or been associated with before. She has had to learn to adjust both physically and psychologically to this new world and learn how to live in it. Interaction with her peers on the ORP has assisted her in this process:

“you are kind of born into this new world and you have got to talk to other people to help yourself understand how you are coping with it I think...Just probably a deeper understanding of my ability really ...learning from yourself I guess and what you can and can’t do.”

(Gabi)

Although some of the other participants were not as articulate as Gabi, they also indicated that they had or were experiencing similar feeling. This appeared to result in improved self-esteem and to the development of a new view of their life. Incorporated in this theme were the notions of a change of focus, self capacity, self awareness, mood, endorphins, normalisation and feeling of freedom. The ORP provided physical and psychological challenges which enabled the participants to test and push themselves, compare their lives to the lives of their peers.
By challenging themselves through the ORP, participants came to the realisation that they were more physically and psychologically capable than they thought, which gave them more drive and motivation to continue on striving. They were able to transfer this learning to their lives at home and came to the realisation that they were able to push themselves physically and psychologically more than they had:

“It changed me, physically and mentally. That’s why I needed it at the time, just needed a push…I think the most important things are the mental and physical challenges, because it can change people. Can push them in the right direction. Those are probably the important things.” (Andy)

The participants were rediscovering themselves and setting new boundaries. They were beginning to think about themselves differently and felt like they now had the energy to do this:

“Totally yeh um getting a bit of spunk back you know? Getting rid of that mental ‘I’m disabled’ thought all the time.” (David)

Eric had been very active prior to his injury and thought that he could never be as active again. This had made him feel depressed and resulted in him lacking motivation and drive. When realising he could be physically active, play sport again and interact with his friends in this way, he changed:

“umm, made things more positive eh,—a lot more positive…Yeah, just mainly made me think a lot deeper than how I was.” (Eric)

Fred noticed that after attending the ORP he had a felt better within himself which has inspired him to maintain this increased level of participation, socialisation and enthusiasm on his return home. At the beginning of the ORP it appeared that Fred did not want to be there. He would often separate himself from the others and talk only to the instructors or his caregiver. I observed this changing as the ORP progressed. He
began to voluntarily join in, contribute and enjoy the other participants company. Following the ORP he reflected back to how he used be and stated that he did not want to be like that again:

“yeah oh it has given me a lot more energy but it has given me a lot more thought of wanting more energy so I want more energy so I can do more stuff, the day when I was sore that sort of put a big thing on me because I don’t want to be like that, so it has made me want to work harder, a lot of things since my accident those first two years that’s how I have done a lot of things too and I don’t want to go back to those first two years. I don’t want to be that sick and I don’t want to get those colds and I don’t want this and that, so everything helps, yeah.” (Fred)

Participants became more aware of their needs and what they had been missing out on since sustaining their injury. David had been a sociable person pre-injury and through attending the ORP had been reminded of this:

“Ah it has made me aware, it’s certainly on that road to being more aware to what’s missing, that I have to rectify that somehow um because I am a people person, I need to be around people. I get a lot out of being around other people um so I need to somehow find ways of rectifying that.” (David)

As the programme progressed the participants surprised themselves with what they were capable of and with this they began to gain a new perspective of their abilities:

“For sure. So when getting through that gate yesterday just wouldn’t have happened, it’s just not something I ever even contemplated.” (Chris)

Part of their rediscovery included beginning to feel ‘normal’ again and to begin feeling better about themselves. This provided them with the confidence to go forward. Participants spoke about how they had learnt
more about what they were capable of. They noted improvements in their mood, which allowed them to become motivated, involved and live life:

“It was good, it was life changing...Just my attitude, more positive, I just want to do things, not like before I went to the course. But since the course I have managed to get out and do more and just happier overall...I just feel different, changed. It’s just being on the course.” (Andy)

Several participants noted that they had gone through a period of depression following their injury and the ORP had impacted positively on this by enabling them to see themselves differently, by physically and psychologically experiencing a change. A number of participants also reported that their family and friends had also seen positive changes:

“I don’t know actually—Could have been still depressed, ah, yeah I still get it now and then, but yeah, always going to have it but there are ways you can control it aye. Just by doing things you want to do.” (Eric)

For some of the participants they were reminded of how they enjoyed their physicality and the thrill they got from participating in physical and challenging activities. This had excited inspired and motivated them, with some of the participants linking the physical challenges and feelings related to this, with an improved mental state:

“Oh man, it’s been a while since my body’s been through something like that, but it was a good feeling.” (Andy)

Participants used the programme as a time to re-evaluate their life. This time was appreciated and was another positive aspect of the programme. By taking themselves away from their usual environment into a challenging and new environment, the participants were given the opportunity to see themselves and their life in a different light. This appeared to start a number of the participants to start thinking about the changes they can make in their lives:
“When I was studying I wasn’t motivated, get my work and stuff, bit of a bad place, just wasn’t focused...to so I took some time off and came on the course. Best decision I made.” (Andy)

A feeling of freedom also developed which allowed the participant the opportunity to do more. They no longer felt confined to their safe lives, to the activities they knew they could cope with. They had pushed their boundaries, faced their fears and learnt what they were capable of and what they could cope with. This had allowed them the ability to get out there and begin to live:

“Hmm I think I am just more, more willing to do stuff when someone asks me if I want to do something. I am even more willing now to go ‘YES’, yeah whereas before I would kind of consider the consequences and ‘what ifs’.” (Bob)

### 4.8 Real Life Consequences

The third level of the results was the ‘real life consequences’. This included the two themes, ‘Getting out there’ and ‘Living and reclaiming’. These two themes are partly similar but can also be distinguished separately in that ‘getting out there’ can be viewed as a precursor to ‘living and reclaiming’. These themes resulted directly from the immediate benefits (‘Learning from peers’, ‘Pushing boundaries’ and ‘Gaining knowledge and skills) that emerged through attendance at an ORP and the secondary consequences (‘Building confidence’ and ‘Self discovery’). Participants indicated that since attending the ORP they were either anticipating becoming more involved or were now more involved in their communities, including social, recreational and leisure activities and they had returned to or were considering returning to work or study. They were setting goals for their future, becoming more independent and as a result
were reclaiming their lives and living life. The ORP appeared to be a valuable experience and has assisted the participants in learning about life with a SCI:

“Well its just life changing, you know, the people you meet, the able-bodied people you meet, the people in chairs you meet. Just the activities you do, I mean it’s not things that you would, being in a chair, it’s not things you’re going to come across every day in your life, but it certainly shows you what’s doable and the simplicity of how you can do things.” (Chris)

Getting out There

This theme includes the concepts of setting goals, gaining independence and participating more. As stated in the previous section, participants felt that following their injury they had become less involved with life compared to the time prior to their injury:

“Probably to begin with, nah I didn’t really, when we got home I didn’t do a lot of it. Like the first sort of 6 weeks where I didn’t have a car but then, yeah it’s hard to say, but definitely not as much as before.” (Chris)

Following the ORP the participants indicated that they were now either planning to or were actually participating more in activities outside of the home. The ORP had provided them with the resources to do this. By learning from their peers, gaining knowledge and skills and being given the opportunity to face fears and push boundaries they now knew they could move forward confidently. They felt they had managed to overcome the psychological and physical barriers that had prevented them from participating:

“Just my attitude, more positive, I just want to do things, not like before I went to the course. But since the course I have managed to get out and do more and just happier overall...Like my friends will come around and sometimes I wouldn’t want to go out kind of thing
because I couldn’t be bothered. But umm, nah, I’ve been going out with my mates, going out quite often, like having dinner, not clubbing.”

(Andy)

Recreationally, participants indicated they were either now doing more or were planning to do more. The ORP had provided them with more options and had shown them what was available in the community. It provided them with the knowledge, skills and confidence to start using their leisure time in a more productive and beneficial way:

“It probably started, my um; it was a nice start to throw myself in a new environment, different activities. It was a starting point for me that has sort of just continued on from the course in trying new things and doing things on my own and going off on my own and things, um, which before the course I was pretty anxious and worried…so it started that whole process for me trying new things.” (Gabi)

Chris noted that although he was still not participating in any recreational or leisure activities on a regular basis he was now using his leisure time productively. He was more actively involved in the running of his household, exercising his dogs, helping friends out, socialising more and had increased his hours at work:

“I’m going to say no, other than being a lot more active with my time. I mean there was a heck of a lot of time just chilling at home watching DVD’s, so a lot more active with my time now if I’m not working. I’m not just chilling out at home doing bugger all.” (Chris)

By experiencing an activity the participants felt they had gained enough confidence to try it again. For example, Bob was able to try kayaking, something he had not previously considered trying and as a result would like to explore this more now:

“I have sort of considered possibly doing the summer course, especially if they are going to be doing some kayaking or other water
stuff because I feel like it has given me confidence now, which I didn’t have in the water before.” (Bob)

With an increased repertoire of recreational options, the participants were able to think and plan ahead. They had gained the confidence to try things on their own and build on the skills they had learnt at the ORP:
“Definitely want to give skiing another try. Really want to see if I can do a bi-ski, see if I can do one of those.” (Andy)

Andy achieved this. The following ski season I spoke with Andy on the ski field after a day’s skiing. He reported to me that the ORP was the best thing he had ever done and he had not looked back since.

Hand in hand with an increase in recreational participation was an increase in regular physical exercise. A number of participants had been very active prior to their injury and very few had returned to this prior to the ORP. They had no longer been able to pursue their previously ‘chosen’ sport and did not have the confidence to get out into the community to look for new options, or perhaps did not know where to start looking. Following the ORP a majority of the participants reported this had changed. For example, Eric reported in his first interview that:
“My motivation last year was pretty slack. I would only go for a push to the end of my house and then back on the couch, real lazy.” (Eric)

Within a month of attending the ORP however Eric was playing wheelchair basketball, tennis, and table tennis. He attributed this change directly to the experience of being on the ORP.

Chris had also been very active and was struggling to return to this because of the limited number of people with a SCI in his community and the limited recreational and sporting options available. Since attending the ORP his motivation to become active again had increased and he had been in contact with a sports coordinator to help him achieve this:
“Yip and she’s trying to drum up numbers to get us enough people here to sort out some team sports as well, basketball or something like that.” (Chris)

Three of the participants had returned to work following their injury, whereas the others had been struggling with the logistics of this before attending the programme. Following attendance at the ORP, several of the participants indicated they were now thinking more actively about returning to work and had developed plans to achieve this goal. One participant, Harry, found that he had gained sufficient confidence and learnt enough about himself to enable him to return to work:

“yeah, well, the course helped a bit to make me more, that I had more self esteem so and because of that I organised the [place of work] more and made it more practical so you can do more [type of work] and it all follows from each other sort of.” (Harry)

Eric had been unemployed since his injury, living in an isolated community and feeling like he could not do much. Following the ORP he felt he now had options and using the confidence he had gained, he independently explored these, set goals and had begun studying:

“Yeah basically when I left the course I came straight to [name of town] and applied straight away.” (Eric)

He had also built up the confidence to find part time work, using skills he had developed prior to his injury. Eric indicated he would have never done this before attending the ORP:

“Nah, nah eh, would have just kept everything to me really.” (Eric)

Following attendance at the programme Fred began to think about going back to work, whereas previously he thought it would be impossible. He began to think about how he could manage to do this and what skills he needed to achieve this. One area he had decided to work on were his personal cares and he had already begun to learn the necessary skills:
“I’d like to get back into work, but that’s another whole thing in its own. I’m just trying new things and how to like do the catheter myself, and that sort of stuff, because if I get left alone for 5 hours, I have to be able to do it myself,...I never really thought much about until I thought about work and stuff and how I can get around it if I am left alone, like if it is just me then I can survive for a day or two. That probably will happen one day.” (Fred)

The gaining of independence is an important part of this theme. A number of participants indicated that through participation on the ORP they had felt independent, a feeling they had lost following their injury. This feeling of independence seemed to have provided some motivation to ‘get out there’:

“Um yeah I was able to be quite independent doing that as well and I think that for me personally that’s my biggest loss with becoming paralysed is losing my independence and I need that, and I found that activity great because it instilled in me that I could still be independent. I was pretty independent in that activity.” (Gabi)

By gaining this independence they could now do things when they wanted and do what they wanted without having to be reliant on others to help. They gained independence in ‘normal’ tasks:

“Just visiting people, just going into town, shopping. I’m doing a lot more of my own shopping and stuff like that, like I pretty much just used to leave that up to [my partner].” (Chris)

This increase in independence also allowed them to be more spontaneous and have a choice in what they did in their lives. They felt like they could now choose activities that provided them with excitement and a challenge instead of continuing to do the activities they knew were safe:

“That was one of the reasons why, I always wanted to travel but just because I thought I couldn’t, I would always need a carer kind of thing. That kind of put me off travelling and doing things and stuff like
that. You know, have to be home at a certain time because my
carer's coming, but since doing my own care and stuff like that I can
do it whenever I want.” (Andy)

By getting out there more, participating in social, recreational and
vocational activities, participants had thought more about their lives and
what they wanted to do. Several participants could now visualise becoming
independent. They had set themselves the goal of attaining this. By
setting goals they began to reclaim their lives:

“It has definitely made me want to go a bit further faster, rather that
thinking three years maybe four years down the track it has made me
want to do it now. It has pushed me, yeah, it has definitely helped,
yep” (Fred)

Participants had begun to look ahead in their lives and dared themselves to
imagine the life they now wanted:

“Ah educational goals would be like ah liaison sports person for [name
of district] disabled sports. That's for education. Sports wise is
mainly to be a role model for the next people who end up in chairs,
yeah…yeah just mainly made me think a lot deeper than how I was.”
(Eric)

Living and Reclaiming

Through ‘Getting out there’, gaining independence and setting goals it
appears that the participants were also reclaiming themselves and living
their lives. By accepting the challenges of the ORP and learning from
these they have been able to look at and evaluate their lives and as a
consequence have chosen to reclaim their life. They realised they could
have a life again that is not determined by their disability. Eric had
changed his life quite significantly. Three months after attending the ORP,
he had shifted towns and was living a busy life dominated by sport,
socialising and study - a life not centred on his disability; centred instead on
pursuing his own goals and living the life he wished to life. He felt he would not be there today had he not attended the ORP:

“I would have still been up in [my old town] for one, yeah, just telling you do what you wanna do, live life yeah...cause I wouldn’t be where I am today I would be still up in [my old town] doing nothing.” (Eric)

Some participants felt like they had reclaimed their lives by becoming independent. For example Gabi had learnt to do things on her own and reclaimed part of herself, feeling psychologically stronger for it:

“but for me I didn’t take the carer that looks after me with all the stuff and all my morning stuff and I think I really worried about not managing without that person and I did, so that was really good for me, cause it made me I think being more reliant on others makes you more anxious and the less you rely on other people and realise you can do it yourself um that probably the better off you are, I find.” (Gabi)

All of the participants had enrolled on the course to gain a new dimension to their lives. They hoped that they would complete the programme with the resources to enable them to do this. They were prepared to be open to the challenges on the ORP in order to have this opportunity. Some of the physical challenges made the participants feel in charge again, just as they had been prior to their injury. This was empowering and motivating, and assisted them in reclaiming and living their lives:

“Ahhh just a bit of, Ahhh, some mental toughness, you know, yeah bit of a push, yeah need a bit of a motivation. Just get in there and just this is my life eh, just as much as possible just like you know despite you know the accident.” (Andy)

They were being spontaneous in their socialising instead of worrying about all the things that could go wrong and weighing up whether it was worth doing or not. They had gained the confidence to participate out in the
community, not allowing their fears and barriers stop them. They felt they now had options available and were using these options to participate recreationally and use their leisure time how they wanted:

“um, well before I was basically just locked in the house yeah doing nothing but now yeah just if I get bored just go out and do something go for a push or go for a drive somewhere meet up with some wheel chair mates usually tennis we play.” (Eric)

Others were making plans as a result of the skills they had gained. Harry had found he enjoyed being back out in the community and realised he could do a lot more in his wheelchair than he had previously thought. He was now making plans to explore his local community in his wheelchair:

“yeah I could do the walk there is, in the [name of area] there is a walk…and so you could do the whole thing with the wheel chair cause it is quite flat…yeah and I do that in the summer…it is wheelchair friendly, so that's a good course I could do in the summer.” (Harry)

The confidence gained through participation has enabled some of the participants to become leaders again and initiate activities and events in their life. Participants spoke of how they were juggling different areas of their life now, to fit everything they wanted to do in, instead of spending excessive hours at home or waiting for others to initiate activities and outings. Andy had gone back to his able-bodied friends at home and surprised them with his motivation and enthusiasm for life. Instead of them motivating him, he had become the driver and motivator:
“They’re amazed; they were like, ‘we should go out and do something like that’, because they have never done anything, city boys. I have told them we should go do some outdoorsy stuff, just get away from the city. It’s better, just get out there where there are no buildings, just you out there, it’s really good.” (Andy)

For a majority of the participants they came to the realisation that a number of the barriers or fears they had before attending the ORP were able to be overcome. Once they had overcome these and were shown what they could actually do, their lives and the opportunities to live life expanded:

“No, more since I have been on the course because before that I thought it was difficult but ah since the course I think that shouldn’t be too difficult. I should be able to do that [talking about travelling]…, yeah you push your boundaries wider and wider with the course. It gets you more self esteem and more, yeah, push your boundaries wider.” (Harry)

In a very simple statement, Eric sums up the effects of the ORP. He reports that he has his life back; he is doing what he wants to do and is not living a life that is restricted or ruled by his injury. He appears to have achieved a balance in his life:

“Ummm for me basically I’m there aye, I’m doing the things I want to do…just do the things I love doing” (Eric)
5 Discussion

This chapter discusses the findings of the study in relation to the experiences and perceptions of eight individuals who attended an ORP in New Zealand. The focus of this discussion is on the relevance of the findings to the lives of individuals with SCI in New Zealand. Initially I will discuss the purpose of the study, followed by an overview of the key findings and the limitations of the study. I will then discuss the clinical implications of these findings and finally make recommendations regarding the direction of possible future research on this topic.

Purpose of study

The purpose of the study was to explore the experiences and perceptions of individuals with SCI who attended an ORP. As mentioned in the introduction, I wanted to know if attendance at an ORP could be an adjunct to their rehabilitation and if so how do ORPs influence outcomes associated with participation, community reintegration and QOL.

It is well documented empirically and anecdotally that the life of an individual who sustains a SCI changes dramatically. As noted at the beginning of Chapter 2, SCI has been described as a biographical disruption. The following two studies highlight how the experience of sustaining a SCI can be different for each individual. Both Dickson et al. (2008) and Duggan and Dijkers (1999) describe the changes with the participants in the Dickson et al. (2008) study focusing on the losses they felt as a result and in contrast the participants in the Duggan and Dijkers (1999) study recounted not only their losses but also the high and turning points.
The participants in the study described in this thesis indicated that their lives had also changed significantly since sustaining their SCI. They indicated that they were not participating in life as much as they had been prior to their injury. For instance, some had not returned to work or study and none were participating in regular recreational or leisure activities. Five of the eight participants appeared to be ‘surviving’ since their injury and not getting any real enjoyment or meaning from their lives. Their lives tended to be dominated by daily cares and governed by the time it took to complete everyday tasks. However, all of the participants appeared to be restricted in some parts of their lives by their fears, their self imposed boundaries, a lack of confidence in their own abilities and the opinions of others.

Anecdotally it appeared that rehabilitation professionals assisted individuals with SCI to learn the skills required to survive but not the skills to actually ‘live life’ to its fullest. A number of previous studies indicate that this may be the case. The participants in Suddick and O’Neil’s (2009) study indicated that although they had been taught a variety of physical and daily living skills in the rehabilitation unit, they did not feel enough emphasis had been placed on the skills needed for social participation and full community reintegration. They reported that the transition back home had been difficult, that the participants in their studies were typically not sufficiently prepared psychologically or physically for home. Life was noted to be very different at home compared with life at the rehabilitation unit.

This reduction in services was also reported by the participants in the Dattilo et al. (1998) study who had lived back in their communities for between one and eight months. They found not only a reduction in support from the rehabilitation team but also a lack of leisure opportunities and
attributed this to a lack of companionship, transport, physical skills and accessibility.

Reflecting on their lives prior to the ORP, most of the participants reported that they were looking for an opportunity to venture out of their comfort zone and to explore new possibilities. The participants described in this thesis indicated that they had reached a point where they wanted to make changes in their life. By investigating and then enrolling in the ORP they were indicating this need. Their needs prior to the course varied, some wanted to learn new skills, some wanted to meet others with SCI, some wanted to see what options were available for people in wheelchairs, while others wanted to escape from their usual life for a while. Some of the participants had initiated the enrolment themselves, whereas others had been coerced into it by friends, family or even case managers, but ultimately the choice to enroll in the programme had been their own.

Research has suggested that to improve the quality of one’s life and to be able to adjust to changes, such as those arising from acquired disability, then people need to have meaning and purpose. In a study by Hammell (2004b) the SCI participants reported that the main contributors to their QOL was feeling like they were in control of their own life, engaging in meaningful activities or planning to do so in the future, using time meaningfully and keeping busy, being able to explore new opportunities, contributing and giving back, and relationships. From the data arising from this study it would appear that attendance at an ORP may provide participants with the skills, knowledge and confidence they were seeking.

Substantive theory

The overall substantive theory that emerged from this study was how attendance at the ORP contributed to the participants with SCI reclaiming and living their lives. The participants indicated they had benefited
physically and psychologically from attendance, with the combination of these gains enabling them to engage more actively in social, recreational and vocational pursuits, and this has resulted in each individual beginning to reclaim or actually succeeding in reclaiming their lives and living their lives. The participants felt that they now had opportunities and options in their lives.

Interestingly, the gains the participants felt they had made at the ORP far exceeded what they thought they would achieve. Some participants reported they had benefited in a multitude of ways, whereas others reported they had benefited in one or two areas. Importantly, attendance in the ORP made an overall difference to their lives, with every participant indicating they had benefited substantially. Indeed, the one participant who had been most reluctant to attend initially possibly appeared to gain the most from the programme. These changes were notable at the second interview where he appeared relaxed, happy to engage in the interview and enthusiastic about the ORP. He indicated he was more sociable, participated more in recreational and leisure activities outside of the home, felt happier in himself and reported that others had also seen this change in mood. He reported he was working towards gaining greater independence which he hoped would enable him to travel away from home and start working again.

The significance of these types of changes and the need to change are supported by the literature regarding successful community reintegration (Luckner and Nadler, 1995; Hammell, 2007; Kleiber et al. (1995; Levins et al., 2004). A number of authors talk about the need for individuals to begin to ‘rewrite’ their lives again after such a traumatic injury. Luckner and Nadler (1995) proposed that the main purpose of adventure programmes is in fact to enable the individual to develop a new life story,
through the development of transferrable skills and insight. The qualitative metasynthesis by Hammell (2007) and the qualitative study by Kleiber et al. (1995) both looking at SCI and QOL, highlight the need for individuals to take control of their life and regain what they perceived to have lost through the engagement in meaningful activities. In the Kleiber et al. (1995) study, leisure was particularly useful and important in this process. This is supported by Levins et al. (2004) who found that by being involved in physical activities, individuals were able to begin to reclaim and redefine their self identity. This, in essence, is what the participants appeared to achieve through completion of the ORP.

The ORP provided the resources, experiences and interactions to assist with beginning to reconstruct and regain control of their life. The ORP allowed the participants the opportunity to explore new ways of living their life with a disability and to think about what was important in their lives. This enabled the participant to build confidence and to go through the process of rediscovery, which in turn allowed them to get out there and live or reclaim their life. The study by House et al. (2009) supports this concept. In this study the caregivers of children and adolescents with SCI were interviewed regarding rehabilitation and participation. The caregivers suggested that by providing individuals with the opportunity to think about and explore their lives more and to participate in a range of activities may assist them in realising the importance of participation in their lives, which may in turn assist in reintegration and improve their QOL. This is the goal of the ORP in this study.

The participants described in this thesis indicated that they had begun to participate more in recreational and leisure, physical and social activities following attendance at the ORP. Prior to the ORP, the participants had reported that they did very little outside of their home and certainly nothing on a regular basis. Several of the participants indicated that they spent a
lot of time doing very little. They felt they were not able to be as spontaneous in their participation in recreational or leisure activities as they had before their injury. They also indicated that they were often reluctant to participate in some activities as they had concerns about how they would manage. After completing the ORP and returning home, the study participants spoke of wanting to increase their participation in recreational and leisure activities and in order to do this they had contacted sports facilitators (e.g. Sports Waikato) to help facilitate local activities, organised trips away with friends (able-bodied and with SCI) and researched facilities and equipment in preparation for future recreation and leisure activities. They found they were using their time more productively and had less ‘down time’ than they had prior to attending the ORP. A number of studies support the use of participation in meaningful recreational and leisure activities to facilitate adjustment to injury and illness and thus assisting with QOL (Barker et al., 2009; Johnson et al., 2001; Krause et al., 1998a; Loy et al., 2003; Lysack et al., 2007; Thompson et al., 2003).

The reported increase in participation of sporting activities and regular exercise as indicated in the results is an important attribute of the programme. Prior to their injuries, seven of the eight participants described in this thesis were participating in some form of regular exercise or sporting activity. Following injury only one participant indicated that they had continued to exercise or play sport regularly. At the follow-up interview the participants recalled enjoying the feeling of being physically exerted on the ORP and felt better as a result. This had given them the incentive to continue once they returned home. The participants indicated that they realised the importance of physical activity for its psychological, physiological, functional and social benefits. Following attendance at the ORP, all eight of the participants were either planning to or were already engaged in regular exercise or sport.
Previous literature has emphasised the importance of regular exercise for physical function, maintenance of physical and psychological health and social interactions. The importance of fitness and its relationship with physical function in highlighted in the study by Shephard (1991) cited in Noreau and Shephard (1995). This study indicated that 25% of individuals with paraplegia were not fit enough to perform the required activities of daily living. If these individuals are unable to carry out these tasks then they would struggle to participate in recreational and leisure activities.

Socially the participants in the study described in this thesis were going out more following the ORP, not hesitating when friends contacted them to socialise and often initiating social contact themselves. Some of the reported increase in socialisation was linked to participation in recreational or leisure activities and some was linked to just wanting to spend time with friends and family. They had gained greater confidence in their ability to cope. Participation in sports, recreation and leisure activities has been shown to be important for both socialisation and social support.

Loy et al. (2003) found that leisure engagement promoted social support which assisted in adjustment following SCI. Hanson et al. (2001) suggested in order to prevent the loss of social roles, exposure to sport should begin early on in rehabilitation. Dattilo et al (1998) looked at the constraints of leisure participation. Social support and companionship were both indicated to be constraining factors by the 14 participants interviewed. They indicated that once back in the community there were not the skilled people around to assist with participation in leisure activities, and that they lacked the companions to do things with. Not all of the participants interviewed for this thesis reported the need for a key person in order for them to increase their level of participation following the ORP. Prior to attendance some of the participants already had established key people in their lives and so this need was not as obvious, whereas others appeared
to make some major changes in their lives and were able to personally drive this themselves. They spoke of now having the confidence to go out and seek opportunities for themselves and to gather people together to support them when necessary. The influence and support from family and friends in relation to participation and reintegration was found to be important in both the study by Suddick and O'Neill (2009) and the Zabriskie et al. (2005) study. Both aimed at exploring the reintegration and rehabilitation of SCI individuals. Hammell (2004b) stated that participation is dependent on the strength of personal relationships.

The ORPs in this study did not necessary use a support person or ‘buddy’ who was known to the participant and therefore the shared experience was unable to be built on once the individual returned home. As all of the participants appeared to have been inspired to increase their participation following the ORP, the addition of a known support person may not necessary improve on the outcomes achieved from these programmes. Alternatively, the ORP provided these participants with the confidence to continue to participate at home in a way that increased involvement of the important people in their lives. They reported being excited about sharing these experiences with their family and friends. Several participants indicated that they were no longer as afraid to ask for help if required. They felt confident in knowing what help was now required and could also see that by asking for help they were facilitating their ability to participate in an activity. However, several of the participants in this current study did report that they had developed friendships with others on the ORP, which had enhanced their lives and allowed them greater opportunities to participate in activities in the community.

Psychologically the participants in this current study felt they were far more positive, happier, content with life and enjoying their life following participation in the ORP. They felt they coped better with barriers and
obstacles in their daily life and had increased motivation to participate in activities of their choice out in their local and wider communities. They had become or were becoming more independent and experienced greater sense of control in their lives, which also gave them the confidence to do more and be spontaneous. They were making plans for the future. They felt by reclaiming their independence they had in a sense reclaimed themselves.

These findings are consistent with the anecdotal findings of Beringer (2004) and Johnson et al. (2001) where individuals with SCI reported that that outdoor recreation assisted in psychological and functional adjustment subsequent to SCI. The meta-analysis by Martin Ginis et al. (2010) also showed a positive relationship between physical activity and SWB. From this study several mechanisms were hypothesised as contributing to this (as are described in Chapter 2). Psychologically Martin Ginis et al. (2003) and Tawashy et al. (2009) found individuals with SCI who exercised regularly had less pain, decrease depression and improved physical function, thus overall better QOL. In a literature review by Devillard et al. (2007) looking at the efficiency of training programmes, positive changes were found in both physiological and physical function of individuals with SCI if they participated in physical activities, other than their normal activities of daily living. Krause (1998a) surveyed 1032 individuals with SCI to identify the factors contributing to their SWB. The results of this quantitative study indicated that by leading an active, engaging life, individuals with SCI gained a greater sense of wellbeing.

Mechanisms of effects resulting from ORPs

The study described in this thesis provides a theoretical framework for a better understanding of the mechanisms by which ORPs may result in the changes in social engagement and participation described in the section above. The results indicated that it was a combination of factors that
created the change. To make these changes to their lives, the participants
needed to gain confidence, physically and psychologically, and they
needed to learn more about their new bodies and new lives following SCI.
These factors appeared to be an essential part in the process of obtaining
the real life consequences reported in this study. Participants had
frequently reported that these factors and in particular confidence in their
own abilities had prevented them from participating prior to their injury.

The majority of the participants involved in the study described in this
thesis indicated they lacked confidence physically and psychologically prior
to attending the ORP and hoped they would gain confidence through
attending. They realised that their lack of confidence was holding them
back from socialising and participating in their community. Following the
ORP all of the participants indicated that their confidence had increased.
This increase in confidence was gained through being able to participate in
the ORP and through this participation they interacted with their peers and
learnt from them, they gained skills and knowledge about life with SCI and
were given the opportunity to push their boundaries. Through gaining
confidence, more things now seemed possible. The participants became
more proactive in their lives. By feeling more confident in their abilities they
were more receptive to opportunities as they presented, be it socially,
recreationally or vocationally. They felt physically more able and therefore
were quite prepared to try new activities and activities they had participated
in prior to their injury but now given away. Psychologically they now knew
that they would cope if something went wrong. They had challenged
themselves on the ORP and succeeded so they know they could do it
again in a different setting. The barriers and obstacles were no longer as
big, or such a challenge.

Previous literature on ORPs for individuals with SCI have also
supported the notion that in order to makes changes in one’s life,
individuals first needed to have a better understanding of their capabilities, gain confidence and start to think about what they wanted in their lives. The results of the two consecutive studies by Kennedy et al. (2005, 2006) illustrate this. Both studies involved interviewing SCI individuals who had participated in a residential activity course similar to the ORP used in the study for this thesis. The first study interviewed participants retrospectively and the second study interviewed individual's pre- and post-programme participation. In total 115 individuals were interviewed using both qualitative and quantitative measures. In both of these studies the participants indicated they had learnt better coping strategies and had come to the realisation that their SCI did not have to limit their life, that they were far more capable than they thought, that people still accepted them despite their injury and that they felt empowered. In the second study, (Kennedy et al., 2006) results indicated a significant increase in satisfaction with leisure, generalised self-efficacy and motivation.

These findings are similar to those of Taylor and McGruder (1996), who used an ethnographic approach to identify the processes that may underline the positive changes seen following participation in sea kayaking for three individuals with SCI. The seven themes that emerged suggested that through participation in a novel activity, with others in a natural environment, positive physical and psychological changes were promoted. Participation had enabled the participants to succeed, feel competent, confront safety concerns and it provided them with a way to use their leisure time and helped them redefine life and themselves.

The gaining of confidence through ORPs has been supported in other literature. McAvoy et al. (1989) found integrated wilderness experiences involving individuals with and without disabilities, enabled the participants with disabilities to: gain confidence in their ability, be more willing to take risks and gain a better understanding of their disability. The confidence
gained through participation in recreation is also supported by Caldwell et al. (1994), who used the constant comparative method to analysis the data collected from 20 SCI participants investigating their perceptions of therapeutic recreation. The participants indicated that the recreation provided then with a sense of hope for the future, encouragement, motivation and confidence and helped them to cope and adjust to their injury.

In the post ORP interviews, the participants in the study for this thesis indicated that the ORP had assisted them to make new discoveries about themselves. This was not an anticipated area of need prior to attending. I speculate that these discoveries arose because prior to the ORP, the participants had been concentrating on just managing to cope with all the changes associated with a SCI and the associated alteration to their daily regimes, and as a result they had not had time to think more broadly about their life direction or their future. Through participation at the ORP they were able to think more about themselves by testing themselves in different physically and psychologically challenging situations and by talking to and observing others and by comparing themselves to others. This enabled the participants to begin to learn what they were capable of, to gain a new perspective of themselves and learn that their lives did not have to be restricted by their SCI. They began to understand what limited their current lives and conversely what motivated and inspired them. All of these factors enabled them to start thinking about the changes they needed to pursue in order to make positive changes in their life. They began to feel better about themselves and in a sense they were rediscovering themselves.

The participants in this study, like all individuals with SCI in general, were young, active and adventurous at the time of their injuries. A number of the participants indicated that they enjoyed being physically challenged again, enjoyed the thrill associated with some of the activities and felt
healthier for it. These experiences enabled them to remember this feeling and encouraged them to want it again. The ORP therefore enabled them to rediscover this about themselves and reconnect with their prior lives in a positive way.

The notion of ORP resulting in self discovery is also supported in the literature. Blinde and McClung, (1997), Coyle et al. (1994), and Lyons (1993) all found that through recreational activities, individuals experienced their bodies in new ways, began to redefine their physical capabilities and were able to test their abilities and skills. This enabled them to rediscover themselves and enhanced their self image, which gave them confidence to try new things. Kennedy et al. (2005) suggested that early introduction to sport assists in acceptance and improved self perception following SCI. The meta-analysis of 96 studies by Hattie et al. (1997), examining the effectiveness of adventure programmes with a variety of population groups indicated that adventure programmes were effective with the largest effect size seen in ‘self control’. Self control included: independence, confidence, self-efficacy, self-understanding, assertiveness, internal locus of control and decision making.

Immediate benefits of participation at an ORP

As we know the above benefits experienced and perceived by the participants in this study are a result of attending an ORP which involved participation in a variety of challenging activities, alongside their peers, in a supportive environment. As illustrated in Figure 1, three themes emerged as the immediate benefits of participation at an ORP. The participants were challenged physically, psychologically and socially. They learnt from their peers about living life with SCI, they gained knowledge and skills from their peers, from the activities they participated in on the course and they were given the opportunity to push their boundaries. These immediate benefits appear to be linked to the concept of perceived self-efficacy and
thus assisted the participant to gain confidence and rediscover themselves which in turn enabled them to get out there and reclaim and live their life.

Previous literature supports the notion that self-efficacy is an important mediator of continued participation, reintegration and QOL following SCI. Bandura (1997) described perceived self-efficacy as “beliefs in one’s capabilities to organise and execute the courses of action required to produce given attainments” (p.3) and suggested it is constructed from four main sources of information: i) enactive mastery experience, ii) vicarious experience, iii) verbal persuasion and iv) physiological and affective states. In the cross-sectional study by Middleton et al. (2007) investigating the relationship between self-efficacy and QOL, a significant relationship was found between self-efficacy and QOL in individuals with SCI, with higher self-efficacy indicating higher QOL. Kessell et al. (1985) looked at a two week wilderness and urban based outward bound experience for chronically ill, physically disabled and able-bodied adolescents, using qualitative and quantitative measures. An increase in personal efficacy (internal locus of control) was shown to be significant in the adolescents who were chronically ill or physically disabled, with the parents of these participants reporting that they found their children had become more independent and more sociable outside of the family. In support of these findings, the study by Boschen et al. (2003), locus of control was revealed to be a common predictor in three of the quantitative regression models for long term adjustment and community integration following SCI.

Through interactions with their peers the participants of the study for this thesis were provided with the opportunity to build their perceived self-efficacy through all four sources described above but in particular with vicarious experience and enactive attainment. All of the participants indicated that the opportunity to interact with their peers was invaluable.
Prior to attending the ORP, five of the eight participants indicated that it would be good to meet others who had similar injuries and were in a wheelchair, but had not realised the significance of these interactions. A number of factors relating to peer support were found to be important benefits of the programme. The camaraderie created by a group of similarly disabled individuals participating and experiencing the same thing together was important as they all understood where each other was coming from and knew what it was like to live with a SCI. The structure of the programme also allowed for the participants to have both formal and informal discussions each day. This created a supportive and nurturing environment which enabled the participants to feel safe and protected and it set the scene for them to push their boundaries, test themselves and start to build confidence. The importance of peer support and peer mentoring has been studied previously.

In a study on biographical disruption following SCI, Dickson et al. (2008) spoke of a need for support groups and peer mentoring, stating that “communication with other people who live with similar injuries may promote recovery and generate a better sense of normality for the injured person” (p. 421). Veith et al. (2006) carried out a small qualitative study to gain an understanding of the peer mentor relationship. The seven SCI participants had all participated in a formal peer-mentoring programme and indicated that the best person to provide support was a person who had lived in the same situation as themselves.

The participants in this study also reported that they learnt about life with SCI from their peers during the ORP. Through this interaction they realised that their injury did not have to restrict their lives and that there were multiple options available to enhance the quality of their life. It seemed to provide the participants with the motivation to continue pushing
themselves and they reported that it was beneficial to see others, some with a greater level of physical disability than themselves trying the different activities. Through the narratives of individuals with SCI, Duggan and Dijkers (1999) reported that interactions with other disabled peers, enabled people with SCI to see how others adapted, coped, and thus assisted them in learning how to improve their own QOL. Once again this emphasises the importance of providing the opportunity for peers to mix.

The participants indicated that they not only learnt practical, physical skills from their peers but also learnt about equipment and resources, and how to negotiate what they had perceived to be physical barriers. This was achieved through observation, conversing, following and competing with their peers. Through my observation, there was always someone they could learn something from. The qualitative study by Levins et al. (2004) supports these findings. In this study looking at the individual and society influences on physical activity participation, the eight participants indicated that the best resource for them were others with SCI, indicating they were inspiring and the best source of information. This is supported in the study by Anderson et al. (1997) who carried out a longitudinal mixed method study to ascertain the efficacy of integrated outdoor adventure programmes in creating positive change for 26 disabled and able-bodied individuals. Amongst the qualitative data, the participants indicated they had learnt new physical skills and made lifestyle changes through attendance. Kinney and Coyle (1992) established that during rehabilitation we needed to identify the recreational and leisure activities important to each individual and proceed to teach them the skills required to participate in these. Through participation in a variety of activities on the ORP used for this thesis, the participants were able to do this and learn what is required to continue in this activity. Although the length of the programme did not allow for full
acquisition of the skills it certainly helped the participant gauge what was needed and started the process off.

Mixing with peers also proved to be very motivating. The participants on this ORP felt that by comparing themselves to others on the programme and then trying to do as well as them gave them the motivation to try harder. This carried on throughout the ORP and then following the ORP, with a number of the participants indicating that they were now challenging themselves as they had realised and decided they could do more or do something better than before. This is supported in the study by Kerstin et al. (2006) where the participants also found that through observation of how well others were doing, provided them with the motivation to do just as well. The studies by Wu and Williams (2001) and Slater and Mead (2004) found that peers were able to provide the motivation to individuals with SCI to become involved in sport and recreation with Slater and Mead (2004) reporting that peers have much more influence than the rehabilitation team.

The team leader role on these programmes appeared to be important. By acting as both a mentor and a role model the team leader appeared to be able to enhance perceived self-efficacy of the other participants through vicarious experience and verbal persuasion. For example, the team leader started conversations off or tried physically challenging things first. The participants in the Boschen et al. (2003) study found that peer mentoring facilitated their adjustment to SCI and reintegration back into the community. In the study by Kerstin et al. (2006), role modelling and competition were emphasised as important motivators to participation. The participants indicated that not only having a role model to follow but also by being a role model to others was invaluable. The authors suggested that
acting as a role model strengthens one’s own ability to participate in physical activity.

Isolation prior to the ORP was a factor for a number of the participants in this study. They indicated that they had felt isolated either geographically or as a result of their injury, with some of the participants acknowledging that they isolated themselves within their homes because of their perceptions of barriers to getting out. They indicated that prior to the ORP they had few opportunities to mix with peers and thus appreciated and benefited from interacting with them on the ORP. The problem of isolation is cited in the literature. In the quantitative study McAweeney et al. (1996) examined the unmet needs of 122 individuals with SCI who had been discharged from the SCI rehabilitation programme. The findings from this study indicated that the most prevalent unmet needs were peer recreation and peer support groups. The participants indicated that they felt isolated from others due to being a minority in society. Noreau and Shephard (1995) also reported that individuals with disabilities tend to feel lonely and lacked social integration more than people without disabilities. They concluded that by addressing this isolation through structured and organised programmes and groups enabled the individual to learn from their peers and through this add value to their lives. These results emphasised the importance of ensuring that peer interaction and support occurs and thus provide support for programmes such as the ORP studied in this thesis.

By design the ORP enables the individual to participate in a variety of activities. These activities provided a vehicle for all four sources of perceived self-efficacy stated above. The variety of activities enabled the participants to see what is available for them to participate in and assisted them in thinking about how they could pursue these activities or similar
activities back in their own communities. Due to geographical isolation, some of the participants had not had the opportunity to try out a number of sports available for them. Following attendance at the ORP the participants indicated that they had learnt about the different recreational and leisure activities available to them as individuals in a wheelchair. Not only did they learn about accessible activities they also realised that they had more options and that there were a lot of activities they could participate in that did not require specialised adapted equipment or support. All of the participants reporting that following attendance at the ORP they were either doing more now or anticipated doing more. Caldwell et al. (1994) found that recreation enabled the individuals to learn about what was available, provided them with information about adaptive resources and helped them develop skills. The importance of providing these options to the individual and providing encouragement to continue in recreational activities is supported by Tasiemski et al. (2006) who examined the continuity of recreational engagement in 985 individuals with SCI.

The experiences of the ORP and in combination with learning from their peers and gaining knowledge and skills, the participants interviewed in this study were able to push their boundaries. This is linked to enactive attainment and physiological and affective states, two sources of perceived self-efficacy. The ORP was viewed by the participants on this study as a supportive, non judgemental environment which enabled them to feel safe and protected. At the same time they were constantly busy and were expected to participate with the group in all activities. They had to change their self care routines in order to be ready at the beginning of each day and then had to try things that they were either afraid of, did not think they would enjoy or had decided they would never be able to do again. In this environment and as a result of participation they realised that they could do far more than they anticipated, they faced their fears, found ways around
physical and psychological barriers and felt motivated to try again. The participants felt they were able to test themselves, push their boundaries, and start to build confidence. This increase in confidence in turn, enabled them to continue to push boundaries once they were home.

The importance of challenge is supported by Dattilo and Murphy (2001) who it to be an important component to the success of the ORP. The authors reported that adventure recreation should focus on involvement of the individual and aimed at their individual skill levels, therefore ensuring that each individual will feel challenged, be motivated to participate and gain from the experience. This increases the effectiveness of the challenge at a personal level and will result in physical, psychological and social benefits and enable the participants to initiate activities in the future. It gave them more options and through successfully participating in a variety of challenging environments they knew they could cope and this gave them the encouragement to do it again. Blinde and McClung (1997) interviewed 23 individuals with physical disabilities to explore the impact of recreational activities on their perceptions of their physical and social selves. The participants indicated that through recreation and sport they were able to challenge the perceptions they had about their body, enhance their beliefs about their physicality and were able to redefine their view of what they were physically capable of, realising they were more physically capable than they thought they were. Coyle et al. (1994) supported this in the findings of their study. They felt that recreational and leisure participation provided the opportunity to test the individual’s physical abilities and skills.

Prior to attending the ORP the participants indicated that they were quite aware that they had limited the amount they did in their lives as a result of fear of the unknown, not knowing how to begin to do a new activity
or attempt an activity they did prior to their injury. Through attendance at the ORP they indicated they were able to work through a number of these barriers. By reducing their fears, confronting the barriers and becoming more motivated, the participants indicated that they now did more. This is seen by the increase in their confidence and discovery of themselves, leading to the real life consequences of getting out there, living and reclaiming. A large number of studies have been undertaken looking at the barriers to participation (Dattilo et al., 1998; Kerstin et al., 2006; Levins et al., 2004; Lyons, 1993; Tasiemski et al., 2006; Vissers, 2008) with fewer looking into how these can be overcome. Boschen et al. (2003) found that those who perceived fewer barriers had greater community integration. The relationship between perceived environmental barriers and perceived community integration was explored by Lysack et al. (2007). One hundred and thirty six individuals with SCI were interviewed. Results indicated that although environmental barriers existed, levels of participation were also high. A significant relationship was found between perceived environmental barriers and community integration with the authors concluding that individuals could get over environmental barriers if they had something meaningful and fun to do, therefore assisting with community integration and QOL.

Overall, the results of this study build on the findings of earlier studies relating to ORP and the components of these programmes to individuals with SCI. The importance of participation in meaningful recreational and leisure activities alongside peers, in improving perceived self-efficacy and confidence and the real life consequences of these gains are highlighted. The findings of the study for this thesis have provided a greater understanding of the lived experience of attending an ORP and provide the basis for further study in this area.
Limitations of study

As for all research, there are a number of limitations to this study. The first one is that this was a small study with only eight participants from only one provider of ORPs. While the data collected from these participants was rich in content and theoretical saturation was reached for the major themes, it would have been interesting to interview individuals who had attended the ORP offered by the other provider in New Zealand to compare data according to programme structure. Unfortunately this did not occur due to the time constraints and number of scheduled programmes during this study. A reduction in scheduled programmes was in part due to less individuals being funded to participate in these types of programmes. Unfortunately I was unable to source any information regarding the criteria for funding of these programmes from ACC, the main insurer and funder of the participants.

The second limitation of this study is that the second interviews took place only three months following completion of the programme. To examine the participants’ views on the long term effects of the programme it might have been beneficial to gather further data six to twelve months following the programme.

The third limitation of the study is that the participants were all enrolled in the ORP prior to enrolling in this study. This raises the question of whether they were already very motivated and thus more likely to gain from participation. However, it is noteworthy that there was one participant in this study who was a reluctant attendee and encouraged to attend by his ACC case manager. Nevertheless, the benefits he reported gaining were equally (if not more) significant when compared to the other programme attendees.
One final consideration in the interpretation of these findings is the role of the researcher in this study. According to constructivist grounded theory the role of the researcher is an integral part of the research and their role and perspective cannot be separated out (Charmaz, 2006). This perspective should be taken into account when reading the findings of this study. For example, my interpretation of the interview data was influenced and informed by my role as participant on the ORP in which I observed the research participants reactions to different experiences and discussed these experiences with them during the ORP. Thus my own perspective of their experience and their relationship with me as research participants were influenced by these interactions. I carried these thoughts into the interviews and they influenced how I asked questions and responded to their answers during the interview.

**Clinical implications**

From the literature and the findings of this study it would appear the through participation in an ORP, or a similar type of programme, individuals with SCI can make physical and psychological gains, which enables them to participate more fully in their lives. As a result, these individuals can begin to more successfully reintegrate back into their community and reclaim their lives. In New Zealand, ‘Back-Up New Zealand’ and ‘Outward Bound New Zealand’ offer the only formal opportunities for individuals with SCI to participate in such an intense and challenging, yet supportive, programme alongside their peers. It would appear that the personal and life changing gains reported by the participants in this study would be difficult to obtain elsewhere in such a short period of time.

Specifically, participation on an ORP programme provides individuals with SCI a significant opportunity to experience outdoor activities in a safe and supportive, yet challenging environment before returning to their own community and trying it there. This enables them to increase their
knowledge about what is required to participate in different recreational activities with increased confidence due to having prior experience and knowledge.

As previously mentioned, a large number of individuals in New Zealand with SCI are either geographically or physically isolated from their peers. This results in them having little opportunity to be exposed to 'experts' with SCI and the knowledge they have. The ORP provides them with the opportunity to interact and learn from their peers about recovery from injury, life with a SCI and reintegration back into the community. This opportunity also appears to enable the participant to set up links and support for the future.

Furthermore, the aim of rehabilitation is the successful reintegration and participation of individuals in their communities. This programme appears to enhance the participants’ ability to do this. They learn about themselves and gain confidence, they begin to explore their world more and start to maximise their potential. All of the participants spoke of increasing their participation, getting out more and ‘living life.’

Clinically, these results also highlight the need for rehabilitation professionals to look beyond the physical needs of their SCI clients and to think more globally and creatively about their clients’ individual needs in order to assist with reintegration back into their community and participation in chosen activities. Physiotherapy, for instance, need to think beyond their role in assisting SCI to retrain basic physical skills and stop relying on the client to initiate their own reintegration and participation needs.

It is suggested from these findings that the ORP could be an important component of the rehabilitation process for those individuals who are finding it difficult to adjust to their injury, are isolated from others with similar injuries and have not reintegrated back into their communities to the
level they had been prior to their injury or wished to be now. The financial cost of these programmes may initially appear significant but should be considered alongside both the positive outcomes that emerged from this study and the cost of providing ongoing physical and psychological rehabilitation services to those individuals who struggle with reintegration or adjustment following their injury. If this comparison is made then the cost is insignificant.

**Directions for Future Study**

The findings of this study have provided a greater understanding about the experiences and perceptions of individuals with SCI who have attended an ORP. As this was a small study it would be interesting to carry out a study involving a larger number of participants in order to get a broader range of participants and experiences. As noted this would be difficult within New Zealand and therefore an international study could be one consideration. In addition it would be of interest to the funders of these programmes to know the long term impact of such programmes and therefore it would be of interest to re-interview the participants six to twelve months following completion of the programme.

To add further weight to the qualitative findings of this study, it would be of value to study the benefits quantitatively. Of particular interest it would be beneficial to compare the pre- and post-attendance changes in perceived self-efficacy, community integration and QOL. Suggested outcome measures for these three areas would be the CHART – Short Form, the Moorong Self-efficacy scale (MSES) and the World Health Organisation QOL Assessment Instrument (WHOQOL) - Bref. The CHART Short Form has been used in SCI populations previously and is designed to measure social participation (Whiteneck et al, 1992). The MSES has also
been used in SCI population studies, with reliability and validity being established for Australians with SCI (Nicholson Perry et al., 2009). The WHOQOL-bref has been used on SCI populations in the past and found to be a reliable measure (Barker et al., 2009).

It would also be valuable to undertake a further similar study, replacing the ORP with urban based non-residential recreational or sporting programmes to compare the findings. I would hypothesis that some outcomes would be similar (e.g. learning from peers and pushing boundaries). This comparison could provide the opportunity to enhance our understanding of the key components of these programmes. Following this a quantitative study could be used to compare participation, community reintegration and QOL of individuals who attend an ORP, individuals who attend community recreational or sporting programmes and individuals who do not attend either. This would provide information on other types of programmes that may produce similar outcomes but may be more accessible either financially and/or geographically. Suggestions for other programmes are: sports teams, gyms, urban based outdoor recreation programmes using local resources and integrated sporting programmes.

Some of the participants in this current study indicated they had either returned to work or had increased their hours at work, following attendance at the ORP. It would therefore be of interest to explore the relationship between attendance at an ORP and vocational rehabilitation programmes in order to ascertain if the participants who benefit from attending the ORP are then more likely to benefit from vocational rehabilitation.

A randomised controlled trial would be beneficial for comparing several outcomes of the participation at an ORP to non-participating SCI peers, able-bodied peers and other disability groups. Unfortunately in New Zealand, this would be very difficult due to the relatively small number of
individuals with SCI and an even smaller number of places available at ORPs. Currently Back-Up New Zealand runs approximately two programmes a year for individuals with SCI and Outward Bound New Zealand offer two places a year to individuals who use a wheelchair for mobility. In order to gain larger numbers of participants, a mixed disability group and a variety of community based recreation programmes would need to be studied.

Finally, it would be of interest clinically to compare the benefits the participants in this study made with other disability groups (e.g. traumatic brain injury). The findings of this comparison could provide further support for the findings of this study.
6 Conclusion

The findings of this study indicated that participation in an ORP has the potential to enable individuals with SCI to be exposed to a number of challenging activities, in a safe and supportive environment with their peers. In this environment they can be provided with opportunities to learn from their peers, gain knowledge and skills and push boundaries which can enhance their perceived self-efficacy. This in turn can provide them with opportunities to build confidence and learn more about themselves, in relation to their new body and new life following SCI. The combination of all of these factors has provided the participants in this study with the resources to start ‘getting out there’; to begin to ‘reclaim and live’ their lives, which appears to have assisted in improving their QOL.

Clinically, this study provides funders and providers of rehabilitation services with reasons to consider ORP as a beneficial adjunct to the rehabilitation and reintegration of individuals with SCI, especially for those individuals who have struggled to come to terms with their injury or who have not successfully reintegrated back into their communities.
References


Appendix 1: Information Letter

Date

Dear Course Applicant,

RE: An invitation to participate in a research project regarding the experience of people with spinal cord injury who participate in an outdoor pursuit programme

My name is Trudi Conway. I am a Physiotherapist working in rehabilitation. I am currently undertaking a research project to complete my Masters degree in Health Science at the University of Otago.

I am looking for people to be in my project and I would like to include you. Please read about my project below and if you think you would like to be involved then either ring Back Up New Zealand or myself to let us know you are interested.

Phone Back Up New Zealand on 0800 503095
Phone Trudi Conway on 07 8658699 or 027 6992688

What is the project?
Experience of Outdoor recreational programmes for people with spinal cord injury.

What is the aim of the project?
To learn about what people with a spinal cord injury who attend an outdoor recreational programme get out of it and what difference this makes to their lives.

The results of this study may help the health professionals working with people with spinal cord injuries to make better decisions about options for treatment and rehabilitation.

What type of participants do I need?
I am looking for people who have a spinal cord injury and as a result use a wheelchair.

What will the participants be asked to do?
Should you agree to take part in this project, you will be asked to talk to me over the telephone and then in two face to face interviews. The two face to face
interviews will be tape recorded to allow me to read through the information you have given me.

The questions I will ask you will allow you to explain to me your experiences and how you feel about them. The questions asked at the first interview will be based around the following: why you have chosen to come on this course, what you think you will get out of the course, how much you got out of the house prior to the course, how much exercise you did prior to the course, what problems you have trying to get out in the community plus some questions about your thoughts on exercising and your general health.

The questions asked at the second interview will be based on finding out what you got out of attending the course, the good and bad things about the course, what has changed in your life since attending the course, whether you have any ongoing difficulties with getting out in the community, what goals you have since the course, and whether you would recommend the course to others.

You will also be given the opportunity to talk about anything else you think is relevant to the study topic. If you ever feel uncomfortable or hesitant talking you will be able to decline to answer individual questions, or ask for the tape recorder to be stopped, or withdraw from the study altogether without being disadvantaged in any way.

Whether or not you participate in the study or whether or not you pull out from the study at any point does not influence in any way your enrolment on the Outdoor Activities Programme or the activities you do while on the course.

After each interview I will listen to the tape and then type up what was said so that it can be analysed. I may employ a professional typist to assist with this aspect of the study. In this situation, any typist thus employed will be required to sign a confidentiality agreement.

**When and where will the interviews take place?**

- I will need to speak to you three times. These times are:
  1. Short telephone conversation prior to the Outdoor Recreation Programme explaining the study and answering any questions you have.
  2. Face to face interview while you are on your Outdoor Recreation Programme. This interview will take about 30 minutes. This will take place in a private room at the programme to ensure confidentiality and at a time when no programme activities are being completed (e.g. during a quiet period in the evening).
3. Face to face interview about 3 months after you have completed your course. This interview will take about 1 hour. This interview will take place at either your home or at another place you choose. Alternatively, if it proves difficult to meet face to face, this interview may occur over the phone.

4. You are very welcome to have a support person of your choice present at any or all of these interviews. Please let us know if you would like to have a support person present so arrangements can be made.

Will there be any risks?
There is always a possibility that the interview will raise issues that may be sensitive for you. If you find that the interview is leading in a direction you do not what to pursue, you may decline to answer, stop the tape or withdraw from the study at any time.
Although every precaution will be taken to protect your anonymity, due to the relatively small number of people in New Zealand with a spinal cord injury there is still a chance that you could be recognised. To protect your anonymity you will always be identified using a false name and any other factors that may help to identify you (e.g. The town you live in) will be removed from all written work gathered from the taped interviews. All people who are involved in this research will treat your information as confidential.

Can participants change their mind and withdraw from the project?
You may ask to stop being in the project at any time without being disadvantaged in any way. You can do this by either contacting myself or my supervisors (see over for contact details).

What use will be made of the information collected?
The results of this study will be published in my thesis. It may also be published in a rehabilitation journal. A summary of the results will also be provided to you and to other interested groups. Any data included will not be able to be linked to you or any other participant. No material which could personally identify you (such as your name or address or other identifying characteristics) will be used in any reports on this study. The written record of the interviews will be securely stored in a locked cupboard and only myself and my supervisors will have access to them. At the end of the project your tape recorded interview will be returned to you. If you do not want it, then I will have it destroyed. As required by the university’s research policy the written records of the interviews will be kept in secure storage for ten years, they will then be destroyed.

Statement of approval
This study has received ethical approval from the Multi-region ethics committee which reviews National and Multi regional studies.
What if the participants have any questions?

If you have any questions about the project, either now or in the future, please feel free to contact me on:

   Trudi Conway
   Phone/fax: 07 8658699
   Cell: 027 699 2688
   trudi.physio@xtra.co.nz

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If you have any queries or concerns about your rights as a participant in this study you may wish to contact a Health and Disability Consumer Advocate, telephone 0800 555 050
Appendix 2: Consent Form

Consent form for Participants in the following study:

Experience of outdoor recreational programmes for people with spinal cord injury.

I have read the information sheet about this project and understand what the study is about. I have had the opportunity to discuss this study. I understand I am free to ask for further information at any stage.

I understand the following points:

- My participation is entirely voluntary (my choice).
- I am free to pull out of the project at any time without being disadvantaged.
- I may have a support person of my choice with me during any of the interviews if I wish.
- The taped interviews will be returned to me or destroyed at the end of the project but the written copy will be kept in secure storage for ten years, after which it will be destroyed.
- I may choose to: not answer any question(s), ask for the tape recorder to be stopped and/or pull out of the interview at any time.
- I give permission for the researcher to access any demographic information (including age, sex, marital status, ethnic group, nature and cause of disability) that I have provided to Back Up New Zealand for the purposes of this study.
- There is no payment for being in the study.
- The results of the study will be presented in a thesis, may be published in an academic journal and will be distributed to interested parties. No material which could personally identify me will be used in any reports on this study.

I agree to take part in this study. I can be contacted at the address and phone below.

Signature of Participant
_________________________________________Date____________________

Signature of Researcher
_________________________________________Date____________________

Trudi Conway
Phone: 07 8658699
Email: trudi.physio@xtra.co.nz
Appendix 3: First interview

- Why did you choose to enroll on this course?
  - (prompts – who recommended course, how did you find out about it, were you supported by others to come)

- What do you think you will get out of the course?
  - (prompts – motivation, get ideas about what I can do at home, for fun, socialization, increase self confidence)

- Did you set yourself goals before coming on the course?
  - Would you like to tell me about those goals?

- How much exercise do you do now?
  - (Prompts - Type, how often, with who?)

- How often do you get out and do things outside of the home?
  - (Prompts - Work, socializing, visit friends, visit family, attend events)

- What stops you from getting out?
  - (Prompts - Transportation, lack of confidence, physical barriers)

- What is your health like at the moment? Are there things you want to change about your general health?
Appendix 4: Second Interview

- How was the course?
- Are there things about the course you would change? Can you tell me about them?
- Would you recommend or encourage people with a SCI to attend this course? Why?
- How has the course influenced you?
- Tell me about the amount and type of exercise you do since attending the course? (Has this changed?)
- Tell me about the things you now do in the community since attending the course? (Prompts: visit friends and family, attend social and community events? Other sport or leisure activities?)
- Has your health changed? How?
- What else has changed in your life since attending the course?
- What do you want to do next?
- Why do you think ACC should fund people to come on this type of course?
- How would you feel if ACC decided to stop funding this course?
- Tell me about the goals you set before the course and then on the course?
- Thinking about the timing of the course in relation to your injury, can you tell me about whether you think it was good time or not and why?
- If you were recommending this course to someone else when do you think it would be a good time to go? Attend?
- Will you tell me about the others on the course? If someone was to do a study trying to demonstrate what people get out of it – what things would you look at?
Appendix 5: Key to transcription conventions

The transcripts for this study reflected as closely as possible the actual words and speech patterns of the interview participants. Interview extracts have been edited to illustrate points for the purposes of this thesis, but all editing has occurred with the intent of retaining the original meaning of the speech. Ellipses (…) have been used to indicate where speech was omitted. Square brackets [ ] were used to insert editorial notes or words not present on the audiotape. Em dashes (—) were used in the place of hanging phrases resulting from an incomplete sentence, interruption by another speaker or where the speaker made a meaningful pause.