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An exploration of social engagement to promote quality of life for people with a spinal cord injury: Exploring the need for a virtual community

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**An exploration of social engagement to promote quality
of life for people with a spinal cord injury: Exploring the
need for a virtual community.**

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A thesis submitted in fulfilment of the requirements for the award of Honours
(Communications) at the Faculty of Communication and Creative Arts.

Edith Cowan University

January 2008

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Secondary Supervisor
Leesa Bonniface

USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

Abstract

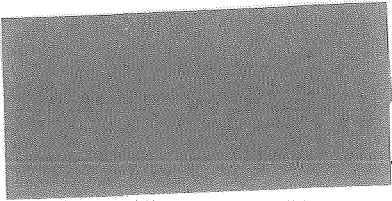
A spinal cord injury (SCI) can significantly alter a person's lifestyle and choices in both the short and long term. An essential area of a person's quality of life (QOL) is that of social engagement, which according to Bath and Gardiner (2005) is made up of *social support*, *social participation* and *social networks*. Studies have shown that although the Internet and virtual communities have the ability to provide social engagement there is little literature covering the area of how they can be used to aid the development of social engagement amongst people living with an SCI post rehabilitation. The aim of this research was to build an understanding of social engagement for people with an SCI and explore whether there is a need for a virtual community that may help promote their QOL through social engagement. Data was collected using a focus group and one-on-one interviews coupled with an online discussion forum. A semi-structured interview format was used for the focus group, interviews and the online forum. This qualitative study was based on themes derived and interpreted from the data. The process revealed that, for the participants in this study, social engagement appeared to be a key factor in the promotion of QOL. *Social support*, which is often reciprocated, was found to be extremely beneficial because it helped develop confidence and self-reliance. Participating in social activities helped to enhance social interaction amongst people with an SCI. Having a more diverse *social network* enhanced QOL for people with an SCI by providing greater opportunities for *social support*. Finally, the potential of social stigma and general lack of accessibility in common community areas were found to be issues that caused psychological stress for people with an SCI. However this seemed to reduce in participants who were socially engaged. A justification and understanding was developed to inform any future development of a virtual community for people with an SCI. This is particularly suited to the predominant group of newly affected SCIs – young adults – who are also primary users of online technology. A virtual community that allows for discussion on the complex nature of SCIs is significant as it provides a forum for support, a location to advertise and encourage participation in appropriate events, and by its very nature, create and enlarge an individual's *social network*.

Declaration

I certify that this thesis does not, to the best of my knowledge and belief:

- i. Incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education;
- ii. Contain any material previously published or written by another person except where due reference is made in the text; or
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Chapter 1 Introduction

1.1 Background

A spinal injury occurs when a human's spinal cord is placed under some trauma (Dawodu, 2007). This can be due to a multitude of different incidents, such as motor vehicle accidents, falls, sport injuries, tumours and disease. A spinal cord injury (SCI) can be devastating to an individual as it can alter their life significantly in both the short and long term (Cripps, 2006). An SCI can occur at different levels of the spinal cord; an injury occurring towards the top of the spinal column results in a greater loss of motor function and sensation for the person affected (Dawodu, 2007). If the spinal cord is damaged in the neck region then the person is usually classified as a quadriplegic because they have impaired movement and sensation to their legs and arms. If the spinal cord is damaged in the mid-to-lower back area then the person is considered a paraplegic having sustained a loss of sensation and movement in the legs and in part or all of the trunk depending on the level of injury.

As a person with an SCI myself, I have experienced the trauma of an SCI first hand after having a severe car accident in 2003. I was injured in a developing country, but was fortunate enough to gain access to a specialist hospital and underwent rehabilitation where I learnt to cope with my condition and adapt to a new way of living.

On completion of the rehabilitative program I was released into the community, and was no longer surrounded by people who also suffered from SCI; essentially, I lost the support that these people provided throughout my rehabilitation. In the community I felt isolated and alone because I perceived to be treated differently. Every new day brought more challenges and I realised the frustration of living in a wheelchair. I could no longer do anything spontaneously - everything that I wanted to do had to be planned to ensure wheelchair access was available. Even socialising with friends and family became an issue because traditional homes usually are not built with wheelchairs in mind.

In my pursuit for information and support, I turned to the Internet to seek out fellow people with an SCI living in the community. There were a few websites that specifically dealt

with an SCI and provided the opportunity for people to communicate (such as the Spinal Injuries Association website in the U.K.). While they provided some benefit, what I really sought was the understanding and companionship from those who had experienced the trauma of an SCI first-hand.

In 2004, the Australian Spinal Cord Injury Register (ASCIR) recorded 381 new cases of an SCI (Cripps, 2006). This rate of injury per annum has been consistent over the past decade (Cripps, 2006). Although, it would be beneficial to focus on reducing this rate of injury, what is important here is that all of the people listed on the register attended some type of rehabilitation program (Cripps, 2006). The problem, however, is that rehabilitation stops (and isolation often starts) once a person is discharged; as such there is a need for ongoing support post hospital/rehabilitation (Cox, Amsters, & Pershouse, 2001).

One way to offer post-rehabilitation support could be to provide an opportunity for enhanced social interaction and engagement between people through the use of online technologies. When people are socially engaged there are benefits that accrue which can enhance QOL (Sherman, DeVinney, & Sperling, 2004; White & Dorman, 2001).

Social engagement, for Bath and Gardiner (2005) includes three components: *social participation*, *social networks* and *social support*. For them *Social participation* involves an individual in social activities; *social networks* involve friends and relatives that are in contact with the individual; and *social support* entails instrumental and emotional support for the individual. When social engagement is enhanced through a combination of these components, QOL may also increase.

Quality of life (QOL) a term generally connected to the health sector and is referred to as 'Health Related Quality of Life' (HRQOL) in the literature (Dijkers, 2005). HRQOL is the underpinning aim of all manner of health promotion activities spurred on by the Ottawa Charter ("World Health Organization", 1986) and the Jakarta Declaration ("World Health Organization", 1997).

The aspects of HRQOL according to the literature include "pain, apprehension, restricted mobility and other functional impairments, difficulty fulfilling personal and family responsibilities, financial burden, and diminished cognition" (Muldon, Barger, Flory, &

Manuck, 1998, p. 542). Specific aspects of HRQOL such as *social support* and *social networks* have been shown to improve QOL for people in traditional communication situations (Bloor, Sandler, Martin, Uchino, & Kinney, 2006). Social engagement has been used as a tool to increase HRQOL through social interaction. Social engagement can reduce the strain on medical services and increase feelings of happiness and wellbeing (Bloor, Sandler, Martin, Uchino, & Kinney, 2006; Manns & Chad, 2001).

If social engagement is a key factor in raising QOL, the use of online technology seems particularly apt in bringing people together for this purpose because it is widely accessible. When people who have endured an ailment come together online what often emerges is a 'community of circumstance' (Cummings, Heeks, & Huysman, 2003). A community of circumstance is an online community that is formed because the members of that community "share the same position, circumstance or life experiences, rather than profession" (Cummings, Heeks, & Huysman, 2003). This is particularly suited for those who have experienced a life-changing trauma such as an SCI. By providing a 'place' for people to socially engage in an online community of this type, people with an SCI may be encouraged to establish relationships with each other and offer mutual support.

1.2 Research Significance

Many people living with an SCI suffer from depression, feelings of hopelessness, anxiety, and distress, as they perceive their QOL has significantly declined as a result of their accident. These detrimental feelings can lead to people having longer stays in hospital, cause longer and slower recovery periods and reduce improvements in a person's general wellbeing (Kennedy & Rogers, 2000a). Ensuring a high QOL and thus averting negative emotional and psychological states, is important because human longevity is increasing, which has implications for the health system broadly. In particular a higher QOL can reduce the strain on services and facilities provided to the community (Bath & Gardiner, 2005).

Increasing a person's mental and physical health through *social support* as a form of social engagement could raise QOL for people with an SCI. Social interaction and *social support* provided by family members, friends and the community are important to individuals with an SCI (Dijkers, Whiteneck, & El-Jaroudi, 2000) and have been shown to increase feelings

of wellbeing (Schulz & Decker, 1985). Finding new and effective ways to facilitate this type of social engagement with friends, family and the community, is particularly significant, since a body of research has documented a decline in family and community ties (Putnam, 1995). *Social support* from individuals who have successfully faced the same stressful situation as the recipient, allows the support giver to provide encouragement in such a way that matches the emotional and practical needs of the recipient (Sherman, DeVinney, & Sperling, 2004). Technology such as the Internet has been shown to facilitate and encourage these ties (Bargh & McKenna, 2004).

Technology and online communities have been shown to successfully deliver support through online social engagement (Memmi, 2006). Virtual communities such as HeartNET create “a portal for communication where they [patients] share experiences and extend support” (Bonniface, Omari, & Swanson, 2006). However, no studies have been identified which directly set about improving the QOL of people with an SCI through the use of online technologies, such as virtual communities.

Social engagement could provide support for people with an SCI and therefore could offer a basis for the development of social engagement through the use of technology. Through the exploration of the benefits of social engagement for people with an SCI, an understanding could be developed that may well be used to promote the use of technology to enhance social engagement and therefore QOL.

1.3 Research Aims and Questions

This research aimed to explore whether a person with an SCI found specific aspects of social engagement to be lacking, or if there were other ways of obtaining a good source of social engagement. In this research the use of a virtual community for obtaining social engagement is explored.

Information was obtained about the aspects of social engagement important to people with an SCI and explored the impact on their lives. The following research questions guided the research;

1. What aspects of social networks need to be fostered for people with an SCI?

2. What role does social participation have for people with an SCI?
3. Do people living with an SCI feel socially supported?
4. Are there other aspects for people living with an SCI that affect social engagement?

Once data had been collected it was used to explore potential advantages of implementing a virtual community to help promote social engagement for people with an SCI.

1.4 Outline of thesis

Chapter two discusses the current literature, which examines the topic of social engagement for people with an SCI. It focuses on research which establishes that virtual communities can provide a venue for social engagement and ultimately raise the quality of life of SCI patients.

Chapter three outlines the methodology used to undertake this research. The justification of the use of interviews, a focus group and an online discussion board can be found in this section.

Chapter four discusses the thematic findings of the research along with the implications for SCI patient support.

Chapter five draws conclusion from the results obtained by the research. Limitations of this research are outlined and some avenues for further research are suggested.

Chapter 2 Literature Review

The term QOL has been used extensively, and in many areas from sociology, and medicine to social history and philosophy (Farquhar, 1995). The literature on QOL may be extensive, but there is no consensus on the definition of QOL or how it can be measured. Never the less the phrase has an immediate connotation and is used because people recognise its mechanisms and intent, which depicts its complexity. Since the definition of QOL is so vague and varied there is a need to narrow the focus of QOL relevant to this study. An aspect of QOL that will be focused on is social engagement, which is grounded by a specific application to people living with an SCI.

Key areas of the literature were examined to develop an understanding of the aspects of social engagement, which relate to the QOL of people with an SCI. To begin, QOL in general was discussed in order to contextualise the over-arching aim of the research. In order to potentially enhance QOL for people with an SCI, the literature pertaining to social engagement provided the main thrust of this review. This is then followed by an overview of leading research regarding virtual communities and their application to supporting various groups of people.

The conclusions drawn from the literature and the results of this study will be used to explore the development of a virtual community that aims to provide an opportunity for (SCI) people to engage socially - which may ultimately enhance their QOL.

2.1 Quality of life

An SCI occurs when trauma is placed on the spinal cord which results in either temporary or permanent change to movement and sensation of the human body ("National Spinal Cord Injury Association Resource Center: Fact Sheets", 1995). SCIs are more prevalent in males in the age group of 16-30 (Dawodu, 2007) than all other age groups, perhaps because this age group is more likely to participate in extreme sports, have less driving experience and are generally more likely to take bigger risks. An SCI affects peoples QOL dramatically as they seek to adapt to a new way of life – relinquishing their previous level of activity.

As a useful separation of the various components of QOL, Dijkers (2005) provided three key categories based on the QOL literature: 'QOL as subjective wellbeing', 'QOL as achievement', and 'QOL as utility'. As *subjective wellbeing*, Dijkers described QOL as "the sum total of the cognitive and emotional reactions that people experience when they compare what they do in life with their aspirations, needs, and other expectations" (p. 88). QOL as *achievement* refers to a person's possessions, relationships and accomplishments - which are usually applied to research about health related quality of life (HRQOL). Finally, as *utility*, Dijkers (2005) pointed out that QOL can be constructed as the outsider's point of view on the person's QOL. These are explained in more detail below.

QOL as subjective wellbeing is internal to every person and is a subjective entity (Dijkers, 2005). This notion has been explored by Scherer and Cushman (2001) in their study of subjective quality of life following an SCI. In their study they explored issues that people perceived about their disability. They discussed issues about participant's satisfaction with their lives as well as the feelings they had about their assistive technology. Dijkers (2005) definition of *QOL as subjective wellbeing* was used as the preferred explanation of QOL for this study.

QOL as achievement explores the physical possessions that have been achieved, but do not include subjective reactions of the participants (Dijkers, 2005). An example of this aspect of QOL for people with an SCI can be seen in a study by Noreau and Fougere (2000) which explored the long-term consequences of an SCI. They examined the participants socio-demographic, educational, vocational, environmental and medical characteristics through a questionnaire, but did not allow the participants to produce their subjective reactions to their achievements.

QOL as utility is the outsider's point of view on a person's QOL in comparison to able-bodied representatives of society. The outsider's point of view is the view of a person who does not have an SCI and has not been immersed in the lives of people with an SCI (Dijkers, 2005). This is often seen in research using quality-adjusted life years (QALYs) and disability-adjusted life years (DALYs), which are instruments that have been developed by the World Health Organisation, to develop an understanding of QOL for people living with an SCI (Murray & Acharya, 1997). An example of research that used

‘utility’ as a QOL definition was a study by Noreau, Proulx, Gagnon, Drolet and Laramée (2000), which gained information from participants using a mailed questionnaire. Participants were asked questions derived from the outsider’s point of view, which in this case was because the researchers had not experienced an SCI themselves. Their study does not leave room for the participants to voice their own opinions and explanations.

The meaning of QOL that has been described according to people with an SCI is that of a subjective measure of life-satisfaction that is strongly influenced by multiple factors. For example, in a study by Hampton and Qin-Hilliard (2004) of the dimensions of QOL for Chinese adults with an SCI, they found eighteen different components, which they separated into five domains: physical, psychological, economic, social wellbeing and restrictive environment. The aspect of their study which has a bearing on this research project, is the social components they define for people with an SCI: social activities, and relationships with family, friends and neighbours. These social aspects are also defined by people with an SCI in a study by Manns and Chad (2001) of people who are quadriplegic and paraplegic.

QOL has been studied in conjunction with people living with an SCI because this is the underpinning aim of rehabilitation (Wade, 2003). Kennedy, Taylor and Hindson (2006) established that the needs of people with an SCI are met during rehabilitation, but that once a person is released into the community their needs go unmet. In 1999 14.5 new cases per million (O'Connor, 2001) were recorded in Australia and this number has increased as a report that was done in 2004 found that 15.3 new cases per million (Cripps, 2006) occurred. Since a person does not usually regain the movement and sensation that was affected by the SCI, each time that a new case occurs it is just adding to the present SCI population. As it has been shown that the prevalence of an SCI in Australia is escalating (Blumer & Quine, 1996), the importance of meeting the needs for those living with an SCI in the community is increasing. Meeting the needs of these people is also significant because with “the level of retrieval, treatment and rehab, life expectancy is close to normal. If you're a 20-year old, you have another 40 years of contending with a severe disability” (Cripps, 2006, p. 28).

A term that is often used in the literature for the subjective part of QOL for people with an SCI is *life satisfaction* and is described as the feelings that a person is concerned with in

relation to their functioning and circumstances (Post, Dijk, Asbeck, & Schrijvers, 1998). A study by Fuhrer, Rintala, Hart, Clearman and Young (1992) explored the link between life satisfaction and impairment for people with an SCI living in the community. They found that a person with an SCI is influenced by their social role and not by the degree of impairment. Therefore, if a person with an SCI has a higher perceived social role they would be more satisfied with their life. Persons who have high levels of *social support*, who are satisfied with their social contacts, and who feel they have high levels of perceived control, report high levels of wellbeing (Schulz & Decker, 1985). These results show that there is a strong possibility that social engagement could lead to a rise in QOL for people with an SCI. However this is a conclusion drawn from the literature and as such it needs to be further examined.

QOL for people with a an SCI for this study will be explored through Dijkers' (2005) interpretation of *QOL as subjective wellbeing* as the cognitive and emotional reactions of the patients. This definition of QOL will be utilised to explore people with an SCI's perceptions of their social engagement. The following sections outline the aspects of social engagement presented by Dijkers and others in the literature.

2.2 Social engagement

Zunzunegui, Alvarado, Del and Otero (2003) explored the link between social engagement, social networks, social integration, and cognitive decline. Social engagement in this study incorporates social networks and social integration. In comparison Mendes de Leon, Glass and Berkman (2003) have eleven aspects related to social and productive activity for people with disabilities, which they categorise as 'social engagement'. Bath and Gardiner (2005) have conducted another study on social engagement which is not as specific as Mendes de Leon's (2003) study, but more specific than Zunzunegui's (2003) study; as such, it provides a middle-ground approach for this honours research.

Social engagement for Bath and Gardiner (2005) is divided into three separate, but related aspects: *social participation*, *social networks*, and *social support*. They describe *social participation* as the involvement of an individual in social activities. Their interpretation of *social networks* consists of friends and relatives that are in contact with the individual and they recognise *social support* as the support provided for and obtained by the individual.

These aspects of social engagement are also explored by Arai and Pedlar (2003) who found that *social support* and participation in leisure activities can increase social engagement.

Social participation can be achieved through sporting activities, community activities, and work and leisure activities. Participation in social activities gives people control over their lives (Boschen, Tonack, & Gargaro, 2003) and is significantly associated with how a person rates his or her health (Hyypä & Mäki, 2003). Participation in physical activities has an impact on environmental and attitudinal barriers for an SCI person and encourages social engagement (Levins, Redenbach, & Dyck, 2004) by giving them confidence and a sense of self worth. Some *social participation* activities require good health and mobility (Lennartsson & Silverstein, 2001). Poor health and immobility can therefore hamper this type of social engagement. For people with an SCI who may have a poor health status, or may be immobile, social engagement would need to be acquired from an alternative source. The level of the SCI has been shown to influence the ease with which *social participation* is encountered and therefore participation occurs less in a person with an SCI with more severe injuries because of the lack of independence and the need for constant assistance (Noreau & Fougereyrollas, 2000). The use of a virtual community for people with an SCI could aid in this participation, through peer support to achieve social engagement, or just by providing a means to discuss any issues that they may have when participating socially.

Social networks consist of the person around a person with an SCI who influence their life, and include friends and family as well as co-workers, physicians and anyone who interacts with a person with an SCI. With a large *social network* the person can discuss issues with a number of people and gain insight from other peoples' perspectives. Through the development of a *social network* the person can develop their *social support* by surrounding themselves with people who can guide and aid them through life. For example, *social networks* can reduce the risk of mortality by aiding in stress management and mental health (Achat et al., 1998). Poor *social networks* and lack of participation in social activities are linked to poorer health status and cognitive decline (Zunzunegui, Alvarado, Del Ser, & Otero, 2003). Online there are examples (Facebook, MySpace, Friendster) of *social networks* that are used to connect people all over the world, which can be utilised to develop *social networks* further. A virtual community targeted specifically at

people with an SCI could develop their *social network* with other people with an SCI, as well as their friends and family.

Social support can be achieved through relationships with peers, friends and family (Barbee & Cunningham, 1995). *Social support* includes emotional support, which can occur through the interaction of people within a support network, as found by Bloor, Sandler, Martin, Uchino and Kinney (2006) in their study on QOL and emotional support. They found that emotional support has a causal relationship with QOL. High levels of *social support* are also linked to greater recovery and better health statuses (Glass, Matchar, Belyea, & Feussner, 1993) through better coping strategies (Palfai & Hart, 1997), increased self-esteem for people with an SCI (Piazza et al., 1991) and peer support from others with an SCI (Sherman, DeVinney, & Sperling, 2004).

Social engagement reduces feelings of depression and depressive states, which in turn reduces health complications that may occur (Derlega, Winstead, Oldfield, & Barbee, 2003). People with an SCI usually suffer from depression (Kennedy & Rogers, 2000a), thus reducing these feelings through social engagement will reduce their health complications. Increasing a person with an SCI's health can contribute to positive self-assessment and positive interactions with friends, family, co-workers and peers (Reitzes & Mutran, 2006). Social engagement and social activity also provide a sense of purpose to a person's life (Mendes de Leon, Glass, & Berkman, 2003). Therefore if social engagement is encouraged a happier and healthy life can be achieved. Persons with high levels of *social support*, who are satisfied with their social contacts, and who feel they have high levels of perceived control, report high levels of wellbeing (Schulz & Decker, 1985). In contrast, poor social connections, infrequent participation in social activities, and social disengagement are linked to a poorer health status (Zunzunegui, Alvarado, Del Ser, & Otero, 2003). These studies show that social engagement has an impact on health and wellbeing, but also a person's health and wellbeing has an impact on the amount of social engagement achieved.

Engaging socially with people in the same situation helps people develop relevant communication networks which can provide an avenue to share experiences (Sherman, DeVinney, & Sperling, 2004). When people with an SCI form connections with other people with an SCI they are able to provide mutual peer support. A person with an SCI

with peer support report better adjustment to their injury and less emotional distress (Sherman, DeVinney, & Sperling, 2004). Some scholars have pointed to the decline in community ties generally (e.g. Putnam, 1995); thus, finding new ways to promote social engagement – particularly among members of the SCI community – is particularly worthwhile. The SCI community is more susceptible to declining community ties because of a lack of access and reduced mobility (McColl & Skinner, 1995), which in turn may increase feelings of isolation and therefore an inequity arises for this community.

Through the investigation of aspects of social engagement (*social support, social networks* and *social participation*) of people with an SCI, an understanding of the benefits that a virtual community may provide can be analysed. Through the development of information about the connection between social engagement for people with an SCI and virtual communities, a better understanding of the use of a virtual community to promote social engagement and thus a raise in QOL can be understood.

2.3 Virtual Communities

A community can be defined as a group of people with similar characteristics (Green & Mercer, 2001). A community provides support for an individual and can influence their social interaction (Dholakia, Bagozzia, & Pearob, 2004). These characteristics could be the geographic whereabouts of the individuals or the interests that the group of people have in common. For this study the common bond between the members of the community would be their SCI. Virtual communities are communities that have formed online due to social interaction (Rheingold, 2000). It is argued that a virtual community is as real and interacts in much the same way as any physical offline community, “one where people talk, argue, seek information, organize politically, fall in love, and dupe others” (Rheingold, 2000, p. Back Cover). The creation of virtual communities via the Internet has become immensely popular over the last few years, especially amongst young adults (Kofman, 2006), and can be found in many forms such as web forums, chat rooms, blogs, and newsgroups. Since an SCI usually occurs in young people (Dawodu, 2007), then the fact that the predominant users of virtual communities are young adults becomes significant. It shows that the Internet has the potential to provide social engagement and thus raise QOL for these people.

The use of computers and the Internet is widespread with 60% of Australian households having Internet access (ABS, 2006), and a large percentage of the public already using the Internet to obtain health information (Brodie et al., 2000). The number of people around the world using the Internet to obtain health information is also increasing (Cotton & Gupta, 2004). The use of virtual communities as a source of health information, and health promotion can be beneficial (Jadad, Murray, Glouberman, Groff, & Stern, 2006) because the information is coming from peers in the same circumstance and thus are termed 'communities of circumstance' (Cummings, Heeks, & Huysman, 2003).

Koh and Kim (2003) define a virtual community as "a group of people with common interests or goals, interacting predominantly in cyberspace" (p. 76). Virtual communities are bound by reference to common objects or goals (Preece, 2001), and not necessarily by personal relations, although at times this may be the case (Koh & Kim, 2003). A gathering of individuals online can only be termed a virtual community when a 'sense of community' (Blanchard & Markus, 2004) arises. A sense of community occurs when participants gain a sense of belonging and build trust between the participants to share emotional connections and be comfortable to interact with the other members of the community (Blanchard & Markus, 2004). Virtual communities can be seen as an example of the evolution of modern societies' way of communicating, which creates abstract social relationships amongst participants (Memmi, 2006).

Virtual communities can provide social engagement through emotional support, instrumental support, and community building (Drentea & Moren-Cross, 2005). "When computer networks link people as well as machines, they become social networks" (Wellman & Haythornthwaite, 2001, p. 326) and have the potential to stimulate social engagement. "[Virtual] communities are networks of interpersonal ties that provide sociability, support, information, a sense of belonging, and social identity" (Wellman, 2005, p. 53).

Online support groups, which can be termed virtual communities, seem to be expanding as the general public becomes more comfortable using computer-mediated communication. White and Dorman (2001) found that virtual community communication can be beneficial for users who may not be able to attend face-to-face group communication. There are problems with communicating using the Internet which White and Dorman (2001)

attributed to the lack of visual and oral cues that are usually found in traditional face-to-face communication, but the benefits that can accrue from communication through virtual communities far outweighs the problems. Online support groups have emerged within health care as a result of the need individuals have to know more about the health conditions that they are confronting (White & Dorman, 2001) and how others have coped with the same ailment.

The Internet has tremendous potential for people with disabilities, especially those with limited mobility, like people who live with an SCI (Dobransky & Hargittai, 2006). "The Internet can be fertile territory for the formation of new relationships as well, especially those based on shared values and interests" (Bargh & McKenna, 2004, p. 586). Since the Internet has only been said to have the potential to create social engagement and stimulate support for people with an SCI, it has not been studied whether their needs are being met by the technology and could benefit further study.

Complex factors contribute to Internet access among people with an SCI, with more barriers among specific subgroups that may not have the ability to use computer equipment. It has been found that a significant QOL benefit can accrue from Internet use by lessening feelings of depression and increasing feelings of self worth (Drainoni et al., 2004). As Drainoni et al (2004) show the Internet could be beneficial for people with an SCI, developing and fostering the use of the Internet for this group of people would be valuable.

Virtual communities can aid in the linking of a peer support group for people with an SCI. A virtual community seems fitting to provide peer support because there is a need for people with an SCI to discuss the issues that they face in the community once they have been discharged from hospital (Boschen, Tonack, & Gargaro, 2003). For this study, the promotion of social engagement could be facilitated through virtual communities. Since the literature shows that a virtual community would be useful to facilitate social engagement and thus create the potential to increase QOL for people with an SCI because virtual communities can be easily accessible and allow people to communicate at their own rate. The Internet is said to be an untapped resource for people with an SCI, which could increase social participation and emotional health by reducing social isolation (Houlihan et al., 2003).

2.4 Conceptual Framework

A conceptual framework (Figure 1) was developed to guide the research for this study. The following figure shows the connections between the concepts introduced in the literature review for a person with an SCI.

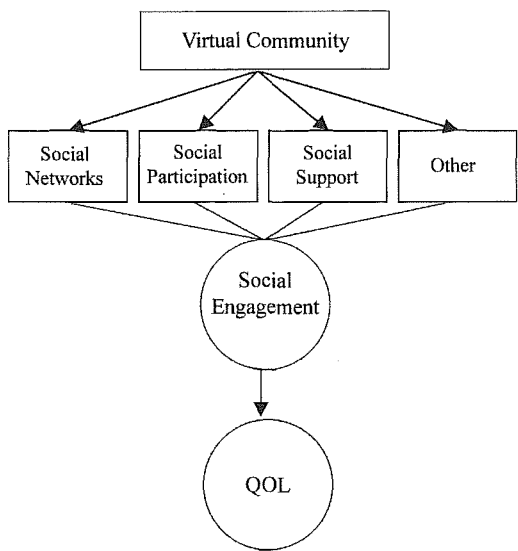


Figure 1. Conceptual framework from an SCI perspective.

This research does not develop a virtual community instead this concept is used as a possible tool for the increase of social engagement and thus QOL for people with an SCI. For this study, Dijkers’ (2005) definition of QOL as subjective wellbeing was used to identify QOL issues. That is an exploration of the aspects of social engagement, which were particularly pertinent for people with an SCI. To define the aspects of social engagement, *social support*, *social networks*, and *social participation* (Bath & Gardiner, 2005) were used as a framework to explore the social elements that affected people with an SCI. The literature identifies that social engagement is connected to QOL for people with an SCI, but it has not been identified whether it has been targeted specifically through a virtual community.

With the increasing spread of the Internet there is a potential to enhance opportunities for people living with disabilities. The literature covering this area of using virtual communities to raise QOL for people with an SCI is not comprehensive and has been

found to be lacking in significant studies and findings. This research aimed to improve the area of virtual communities for people with an SCI by developing concepts associated with the development of an understanding of social engagement for people with an SCI.

The literature defines a need for a person with an SCI to interact with others in the same circumstances, it supports that a virtual community, which promotes a 'community of circumstance' (Cummings, Heeks, & Huysman, 2003), could be beneficial. A virtual community could provide the *social support* and interaction that a person living with an SCI finds to be lacking in the current community.

The conceptual framework lead to the development of the following research questions for this research:

- What aspects of social networks need to be fostered for people with an SCI?
- What role does social participation have for people with an SCI?
- Do people living with an SCI feel socially supported?
- Are there other aspects for people living with an SCI that affect social engagement?

The four questions have been developed too analyse each of the three aspects of social engagement that Bath and Gardiner (2005) found. The extra question incorporated anything that did not apply to the aspects of social engagement as defined by Bath and Gardiner (2005).

2.5 Summary

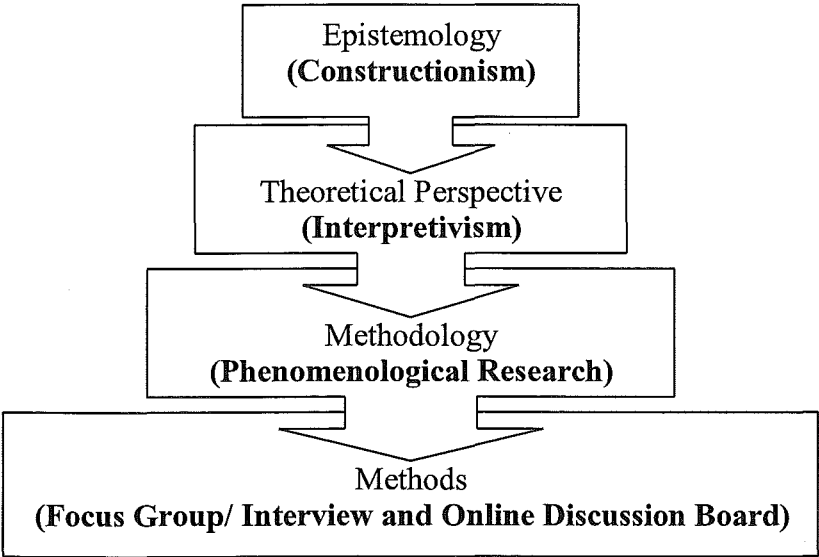
There is extensive literature that explores traditional communication and social engagement for people with an SCI, but there is a lack of literature that examines the use of virtual communities for people with an SCI. This thesis will address this area and strive to develop an understanding of the link between virtual communities and people with an SCI. A traditional form of social engagement, which takes place offline, has been shown to aid in the wellbeing of a person with an SCI (for example Fuhrer, Rintala, Hart, Clearman, & Young, 1992; Kleinman & Rosenblum, 2004). There is a need for social engagement within the community, thus finding new ways of facilitating this type of engagement would be highly beneficial for people with an SCI. The Internet can be used as a new way of

providing social engagement for people with an SCI and thus creates the potential to increase QOL (Houlihan et al., 2003).

Chapter 3 Methodology

3.1 Approach

This section outlines the methodology used for this project. Given that there is a lack of rich research which addresses social engagement for people with an SCI through the use of the Internet, an exploratory study would be beneficial for the research community. Qualitative research methods were used, which allow for the discovery of patterns which emerge after close observation, careful documentation, and thoughtful analysis of the research topic (Freebody, 2003). What can be discovered by qualitative research is not sweeping generalisations but contextual findings. The qualitative approach chosen for this study retrieved data through a focus group, one-on-one interviews and an online discussion board to identify relevant themes. Crotty’s (1998) scaffolding framework is useful in categorising the research approach used in this study. His approach identifies four hierarchical categories used to outline key research elements: epistemology, theoretical perspective, methodology and methods.



(adapted from Crotty, 1998)

Figure 2. Diagram of Crotty's (1998) methodological framework.

Crotty (1998) described epistemology as the overarching body of knowledge that is being researched. He described how this then leads to the theoretical perspective, which informs and provides a context for the methods being used to collect the data. One of Crotty’s tiers

in his framework is called methodology, which he describes as the plan and rationale for the methods being used in the research. The methods, as Crotty (1998) describes, are the specific tools that are used to obtain information for the research. The four categories are discussed below as they apply to this research.

The *epistemology* for this thesis follows that of constructivism which recognises that several different interpretations of the same thought can occur, and as such creates variation (Papert & Harel, 1991). Therefore constructivism is used to find multiple meanings of how participants engage within their world.

The *theoretical perspective* which adds to the constructivist epistemology for this thesis is interpretivism, which analyses what the participants think within their social context, and allows for multiple thoughts to form and interconnect (Hussey & Hussey, 1997). This perspective allows for meaning to be created through a debate both for and against in relation to its cultural context (adapted from Crotty, 1998). Interpretivism analyses the interactions between the participant and society, the interactions that the participants partake in everyday life and their reactions to the social structures imposed on them (Goldman, 1999).

The third tier of Crotty's framework (methodology) for this study is *phenomenological*. *Phenomenological* research recognises the participant as inextricably linked to their environment and the way in which they experience this (Crotty, 1998). Phenomenologists believe that the only reliable source of information is the participant (Groenewald, 2004). Thus, the data obtained from the methods create a renewed body of knowledge.

The methods used to obtain data were a focus group and interviews and an online discussion board. Initially four focus groups with between two and four participants in each were planned. Once the process of recruitment was under way it became apparent that this number of people was not going to be possible and as such only one focus group consisting of two members and two one-on-one interviews were conducted. The methods chosen are explained and justified in the following section.

Validity and reliability are required within the theoretical perspective of interpretivism to legitimise the research (Kelliher, 2005). Validity occurs when multiple methods are used to collect and the data is then analysed for convergent validity (Arnould & Wallendorf, 1994).

The use of multiple methods for data collection contributes to a key principal of triangulation. Triangulation for this research occurred by obtaining and comparing results from a focus group and interviews with an online discussion board. The researcher's SCI also aided in validity because she could draw from her own experience to estimate the kind of data sets that could be produced. This can introduce bias but to minimise bias the researcher was conducting the research in an area the participants were comfortable in, to encourage discussion. Building trust between the researcher and the participant can reduce the introduction of bias to the research, thus this was sought. The questions posed to the participants were open-ended to reduce bias and ensure that they were not leading to a required answer. Reliability occurs when the results are consistent and replicable (Golafshani, 2003).

3.2 Research Design

This study aimed to build an understanding of social engagement for people with an SCI and develop an understanding for a virtual community that may help promote their QOL through social engagement. A phenomenological approach aids in this exploration by analysing how a person with an SCI react within their environments and become socially engaged. The data was obtained through a focus group and interview discussions and an online discussion board. The strategy used to achieve the research aims included a plan which guided the data collection, from who, how and when data was collected to how it was analysed. The justification of the use of a focus group and an online discussion board is discussed in this section.

A necessary function of effective focus group interview discussions is social engagement (Mazza & Berre, 2007). Given that the topic of this research, this method is particularly apt for the research. Focus groups are said to be a valid tool in social research, they are useful for obtaining descriptive data for specific groups of the population (Bender & Ewbank, 1994), in this case people with an SCI (see Table 1). Focus groups can provide rich, detailed and valid data that generally does not alter the participants' perspectives (Stekler

et al, 1992 cited in Bender & Ewbank, 1994).

Table 1. Participant Information (Focus group and interviews)

Data Collection Type	Gender	Injury Level	Time Since Injury	No. of Participants	Age of Participants
Focus Group	Male	Paraplegia	16 years	2	18, 27
Interview	Female	Paraplegia	20 years	1	23
Interview	Male	Paraplegia	23 years	1	35

Due to the nature of the online discussion board being anonymous the type of data that was retrieved about the focus group and interview participants (see Table 1) could not be achieved from the online discussion board participants.

During focus group and interview discussions the participants could offer socially desirable perspectives. That is, the participants may feel uncomfortable talking about certain issues in a focus group discussion (for example issues pertaining to sex and relationships) and offer answers which essentially ‘save face’. The participants may also try to anticipate what the researcher wants them to say within the focus group discussion. These outcomes can be minimised when the participants are anonymous as they are when using the online discussion board.

Online technologies, such as discussion boards, allow for the exploration of cultures and communities that form online; it can be used as a tool for the exploration of general topics (Langer & Beckman, 2005), which in this case is social engagement for people with an SCI. Discussion boards are websites, which are frequently updated, and allow participants to become involved anonymously at their leisure (Kozinets, 2002). The fact that participants can take part in the online discussion board whenever and from wherever can yield rich data.

3.3 Data Collection Procedures

3.3.1 Recruitment

Flyers (Appendix I) were placed in areas that had a high possibility of being seen by people with an SCI, to recruit participants for the focus group and interviews. This included places where people with an SCI meet to play sports. The SCI unit at Shenton Park was also contacted to recruit participants, but due to the research focusing on participants being at least a year post injury the spinal unit said that it was unlikely that many people would come forward to participate. The equity and diversity officers at the five universities in Perth, were contacted to gain approval for flyers to be displayed around their offices. The equity and diversity officers also contacted the people that fit into the researchers target group on behalf of the researcher to see if they were willing to take part. The ParaQuad Association in Perth, which helps people with an SCI to reintegrate into the community, was contacted for this research. The ParaQuad Association contacted some of their members on behalf of the researcher to encourage them to take part in this research. None of these methods of recruitment proved fruitful. Due to the lack of participants taking part in the focus group and interviews, all of the participants had to be recruited from one organisation: The WA Disabled Sports Association.

The WA Disabled Sports Association was contacted to recruit participants for the focus group and interviews that were conducted in association with the organisation. The WA Disabled Sports Association were provided with information about the people that were being targeted for this research; aged between 18 and 35 years and at least 12 months post discharge from hospital. The WA Disabled Sports Association then contacted their members that fell into the category and arranged the time and dates of the focus group and interviews. Once the participants had agreed to take part in the focus group and The WA Disabled Sports Association had arranged the meetings, the researcher was provided with the information about how many people to expect at the meetings and at what times. The participants were segregated into small groups and were divided into male and female groups because the discussions may have been intimidating for some participants if they were in mixed company. It was arranged for three meetings to take place, which ended up consisting of four people in total (see Table 1). For the female group meeting one person

turned up therefore the focus group became a one-on-one interview. One of the male groups attracted two members where as the other attracted one. Thus one focus group session and two one-on-one interviews were conducted to obtain the data.

3.3.2 Focus Group and Interviews

The participants consisted of four people aged between 18 and 35 (See Table 1). The participants had been living with an SCI from 16 to 23 years. Initially, three focus groups were planned, however, due to the recruitment problems identified above only one focus group attracted sufficient participants ($n=2$) to be undertaken. The researcher interviewed the remaining two individuals recruited one-on-one. All of the participants are members of the Western Australian Disabled Sports Association.

The focus group allowed participants to be involved in negotiating a shared meaning (Goss & Leinbach, 1996) about social engagement and how it related to people with an SCI. This instilled confidence in the participants and built rapport. Given focus groups can be intimidating for shy members who are unable to articulate their views to the group (Krueger & Casey, 2000), the researcher ensured that each member of the group had a chance to voice their opinion and no member of the group dominated the conversation. The participants in the focus group and interviews were made aware of the discussion board website at the end of the session, and were informed that they could use the site to discuss other issues or elaborate on things they were not able to say, thus providing a secondary source of data in an anonymous and less intimidating environment without the face-to-face contact that can intimidate some participants (Bloor, Frankland, Thomas, & Robson, 2001). The interviewees were provided with the contact details of a counsellor should they need to discuss any issues that were raised during the discussion.

The focus group and interview sessions were conducted at the Herb Graham Recreation Centre where the WA Disabled Sports Association is based. The sessions started with the participants being asked to read the 'letter to participants' (Appendix I) and to sign the consent form (Appendix I). Time was also allowed for the participants to ask questions. After consent had been obtained from each participant a warm up exercise was conducted by handing out the questions on a sheet of paper and the participants were allowed to gather their thoughts so that they did not feel 'put on the spot' during the discussion. The

researcher discussed her SCI to try and make the participants feel at ease and build rapport after the paper and pencil exercise had been conducted. The research then continued with the semi-structured question plan (Appendix I). Time was allowed at the end of the session for any further comments. It was estimated that each of the sessions would last between one and a half and two hours. Once the meetings were conducted all of the meetings were finished within an hour.

The focus group and interviews were transcribed soon after the event to ensure that researcher reflections could be easily recalled and footnoted. The synchronous nature of the discussion board meant that archiving and thus transcription was immediate.

3.3.3 Discussion board

The online Discussion Board was established to add weight to the interview data, particularly because it had proven difficult to attract participants in person. Like the focus group and interviews four participants took part, but in comparison there were three females and one male. These participants posted comments on the Board, even though a further five had indicated their interest in the study and were given access. The participants who used the discussion board were from both developed and developing countries around the world: 2 from Africa, 1 from USA and 1 from Europe.

The discussion board was created using the Google Group's facility (a screen shot can be seen in Appendix II) with the web address <http://groups.google.com/group/spinal-cord-injury-and-social-life>. The home page incorporated a consent statement (Appendix II), which informed potential participants that participation on the discussion board renders their consent to the data being used in the research. To recruit participants for the online discussion board the researcher publicised the website on other sites that discuss SCIs (The SIA website in England, several Facebook groups and the Australian website enable.net.au). The Google Group was monitored on a daily basis and the researcher was actively involved by stimulating discussion through the use of questions that were developed for the focus group and interviews. There was also a more general section thread where the members were encouraged to discuss how they acquired their SCI in order to collect relevant data that may not have been gleaned from the initial questions. The discussion group was run during the data collection period of 20 weeks.

3.4 Data analysis methods

Once the data had been collated and transcribed the data was analysed manually by printing the transcripts and going through each transcript with highlighters to develop the codes found within the data. The data set was continually being analysed and added to throughout the study and used to provide insights into the themes that were being produced. The data was analysed through the use of Strauss and Corbin's (1990) grounded theory coding system.

The grounded theory approach is a qualitative research method that uses a set of procedures to develop grounded theory about a phenomenon (Strauss & Corbin, 1990). For Strauss and Corbin (1990) there are three stages of coding the data that develop the phenomenon: open coding, axial coding and selective coding. Open coding breaks down the data into small discrete pieces of information that can be placed into categories and axial coding places the categories found during the open coding procedure into a context for the category. Selective coding, finds the underlying storyline through the data by relating the subsidiary categories and validating the relationships against the data and producing a core category. Although grounded theory was not addressed in this research, their coding philosophy provided the basis for a simplified coding process to be utilised in this exploratory study.

Bath and Gardiner's (2005) categories of *social participation*, *social networks* and *social support* were used as broad 'open' codes, the data was broken down into more specific categories under each of the open codes. For example by using Bath & Gardiner's (2005) category of *social networks* a subsidiary code of *family* was identified. The data was then examined further to identify key themes within these categories. For example under *social networks*, the *friends*, *family* and *relationships* codes were constructed as providing the theme of **dysfunctional relationships**.

The focus group and interview data were compared to the online discussion board data because the targeted groups had varying levels of social engagement. This triangulation of the data aided in the understanding of the different 'levels' of social engagement experiences by the participants. Primarily this was necessary because the focus group and

interview data set came from a sporting team and thus they were already participating socially. The data set for the discussion board seemed to show that some people lacked social engagement whereas others had a very active social life.

3.5 Summary

This chapter outlines the methodology used for this thesis. The methodology was developed with the use of Crotty's (1998) framework. The methods that were used to obtain the data were one focus group, two interviews and an online discussion board. Due to the problems with recruitment the methods had to be changed and adapted for a small data set. This phenomenological research was based on an interpretivistic theoretical perspective. The epistemology for this research was constructionism. The participants for this research were aged between 18 and 36 years and were at least twelve months post their spinal cord injury. The recruitment process to obtain participants within this target group proved problematic and led to changes in the methodology. Initially the aim was to have four focus groups consisting of four people each, thus sixteen people in total, but due to the lack of participation only one focus group could be held along with two one-on-one interviews. The data that was obtained was coded manually by printing the transcripts and highlighting recurring phrases to develop the codes.

Chapter 4 Findings and Discussion

This section details the findings obtained from this study, which explores the concept of social engagement for people living with an SCI. The methods used for obtaining the data were a one-hour focus group, two one-hour interviews and an online discussion board.

All of the participants in the focus group and interview sessions were members of the WA Disabled Sports Association and as such all belonged to a sporting team. This data was collected from four participants aged between 18 and 35 years (See Chapter 3, Table 1). One focus group and two one-on-one interviews were conducted with those who agreed to participate.

The online discussion board was used for triangulation and to add weight to the interview data. Four participants contributed to the data produced on the discussion board.

Once the data was collected it was examined in relation to the research questions (Table 2) that pertain to social engagement. The research questions were derived through the use of Bath and Gardiner’s (2005) three categories of social engagement; 1) *social networks*, 2) *social participation*, and 3) *social support*. A fourth research question was added to identify any aspects of social engagement which might not have been revealed through Bath and Gardiner’s (2005) categories.

Table 2. Research questions for social engagement

RQ No.	Research Questions (RQ)
1	What aspects of social networks need to be fostered for people with an SCI?
2	What role does social participation have for people with an SCI?
3	Do people living with an SCI feel socially supported?
4	Are there other aspects for people living with an SCI that affect social engagement?

Bath and Gardiner’s (2005) three categories of social engagement provided a useful starting point for this analysis, because they could be used to conceptually separate the data into three identifiable categories. By using the coding system described in section 3.4 the

data was examined manually by searching for repetitive words and phrases in the dialogue. Figure 3 identifies the codes and themes that the data produced.

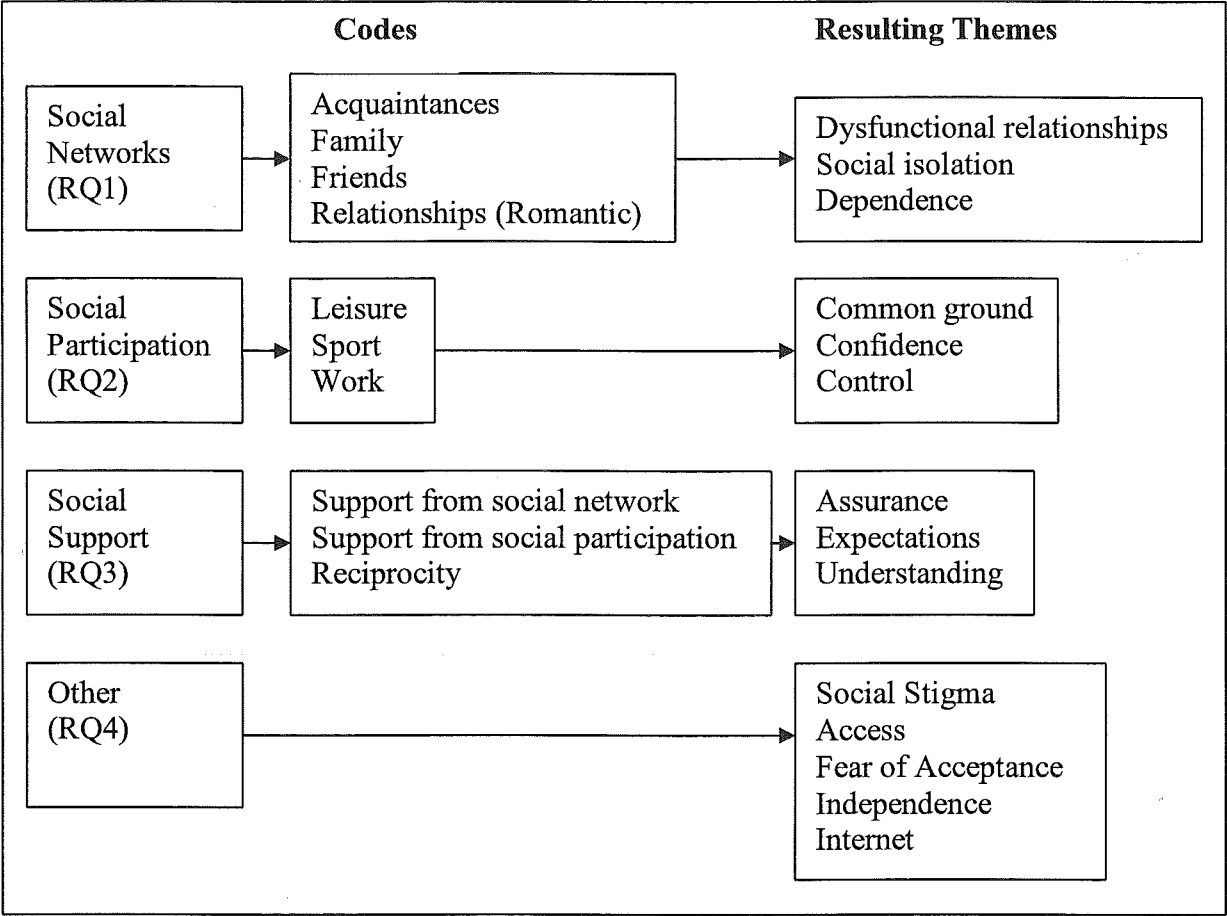


Figure 3 The way that the themes were produced from the data

The specific themes derived for a person with an SCI under each of Bath and Gardiner’s (2005) three categories are discussed below according to the four research questions identified. The following sections are presented according to the method of collection: that is, the focus group and interview data is presented first, followed by the discussion board data. However, it is important to note that while these codes have been usefully separated for the sake of simplicity, there appears to be some interrelationship between the categories. As such, further research would be required to map these complex relationships. This qualitative study, however, provides a rich description of social engagement for the people with an SCI in this study.

The data was obtained from the transcripts of two interviews (from two people), one focus group (from two people) and nineteen posts (from four members). The frequency that the codes were found in the data are portraying in the following table (Table 3).

Table 3. Frequency that the codes were found within the data.

Codes	Frequency
Acquaintances	4
Family	6
Friends	20
Relationships	5
Leisure	7
Sport	7
Work	6
Reciprocity	9
Support from social network	6
Support from social participation	3
Social Stigma	6
Access	9
Fear of acceptance	5
Independence	5
Internet	4

4.1 RQ 1. What aspects of social networks need to be fostered for people with an SCI?

In response to research question 1, *social networks* were found to be those people who the participants in this study identified as interacting with, either on a daily basis or from time to time. Thus the *social networks* consisted of ‘acquaintances’, ‘family’, ‘friends’ and ‘relationships’ (Figure 3). Based on these networks, the following themes are discussed in the following sections: 1) **dysfunctional relationships** 2) **social isolation**, and 3) **dependence**.

4.1.1 Focus Group and Interviews

Richard who took part in the focus group and interviews had been injured for a considerable amount of time and thus had developed his *social networks* for the most part while being in a wheelchair. He predominantly discussed his *social networks* in relation to his friends, family and romantic relationships. These categories produced the theme of **dysfunctional relationships** from the focus group data.

Richard described how his SCI had a negative impact on his *social networks*. He was injured at the age of three years.

It [his spinal injury] had a major impact on family and friends. I just had a bit of a troubled childhood especially towards family and friends. I fell into the drug scene and mixed with the wrong crowds. (Richard)

Although, the data cannot reveal the relationship between his injury and his tendency towards drug use (i.e. even if the participant had not been injured he may still have “fallen into in the drug scene”) his SCI may have contributed to his drug use as a result of his **dysfunctional relationships** with his family and friends. It is well documented e.g. Kennedy and Rogers (2000b) that those who suffer from an SCI experience varying levels and durations of depression. Some people who have been injured at a young age have found that their families ‘smother’ them and treat them as invalids in an attempt to protect them from the perils of the world (Vogel, Hickey, Klaas, & Anderson, 2004), which could possibly cause **dysfunctional relationships** to occur. This could have been the case for Richard although he did not offer any further comment on how he was treated as a child. It is, conceivable however that Richard’s ‘troubled’ childhood in relation to his **dysfunctional relationships** between him and his family and friends resulted in his search for new kinds of *social networks*, ones which were tied up in drugs and the ‘wrong’ crowds. The Internet, in the form of a virtual community, could have provided a means for Richard to discuss his feelings with others who understand. Although **dysfunctional relationships** may still exist in the lives of some people with an SCI, virtual communities can provide a supportive environment in which to discuss such issues.

4.1.2 Discussion Board

The four discussion board participants had been living with an SCI for a shorter time than the focus group participants and thus have spent a large portion of their lives as able-bodied people. The discussion board participants had *social networks* that consisted of people who knew them before and after their SCIs. The themes produced by the data for the discussion board were **social isolation** and **dependence**.

A person's *social network* may be lacking if they are injured in their late teenage years or early twenties because their friends and family may have difficulty seeing past the wheelchair (Carpenter, 1994) and as such may experience **social isolation**. Kate, who was injured at the age of 23 years, discussed her *social network* as lacking; she seemed to restrict her social interaction by keeping busy either at work or at the gym.

I really do not have a social network... or so I could say... my days are like... home-work-home, gym on Saturdays, when possible visit the supermarket. My friendship is on phone call only... no personal visits from friends. I am either at work or at the gym and when I am home really no visits, apart from family [...] I really do not want to meet people I knew in my previous life. (Kate)

Kate does not make clear the reason for her family being the main part of her *social network*, but it is possible that she is afraid of what her friends and the general community might think of her new life (as opposed to “previous life”), thus she may feel **social isolation**. She may just want to build up a new *social network* so that the people within her *social network* would not be able to compare what she was like before to what she is like now with her SCI. Some of the people in a person's *social network* may not be able to handle being a part of the life of a person with an SCI and thus remove themselves from that person's *social network* (Carpenter, 1994), which can cause **social isolation**. If this is the case, face-to-face interaction may be difficult for Kate and as such the telephone seems to act as a proxy for social interaction. The telephone may provide her with some distance from the person that she is talking to as well as providing some semblance of anonymity (Cox, Amsters, & Pershouse, 2001). Kate may also find that she feels socially isolated because of her work and gym expectations and thus rendered her *social network* as lacking. It is also possible that Kate is just too busy to actively participate in her *social network* to the degree that she desires, but she does not make this clear. The use of a virtual community may provide people like Kate with an avenue for connecting with the members of her *social network* and therefore may reduce **social isolation**. As Kate seems to be very busy during the day, the 24-hour accessibility of the Internet could encourage her to participate in a virtual community.

In contrast to Kate, Isabel (injured at the age of 21 years) has a diverse *social network* and appears to be socially engaged because of the rich and varied nature of her *social network*:

[My social network is] mostly made up of friends from work and university, and friends that I know through my boyfriend. It is quite a varied network, made up mostly of able-bodied people, although I have a small number of close friends (disabled) through sports/other disability-related activities, and a large number of acquaintances from the same sources. (Isabel)

It appears that Isabel finds having a diverse *social network* provides her with a rich source of support. A study by Achat et al. (1998) found that large *social networks* are positively linked to the available support that a person can obtain. They also found that a large *social network* provided more opportunities for companionship (Achat et al., 1998), which can combat feelings of **social isolation**.

Given that an SCI usually happens to a person between the ages of 16 and 30 years (Dawodu, 2007) when people are gaining independence, being afflicted by this kind of injury can cause partial or complete **dependence** on others. By widening a person's *social network* it may be possible to create a situation where **independence** is achievable. Isabel, who seems to have a diverse *social network*, commented on access to her friends' houses and how they have tried to make their houses accessible to her as well. She finds that because she was injured in her early 20's and her friends are around the same age, making the houses accessible was easier because her friends were just starting to settle down and move out of home into their own houses.

My closest friends have made their houses as accessible as possible. In this respect, it was helpful being injured at the age of early 20s, as most of my friends are now settling down, and are choosing houses that are accessible with relatively little trauma. (Isabel)

Isabel had the advantage of living in a developed nation with access to rehabilitation, unlike Kate who lives in a developing country. She found that even though the rehabilitation was necessary to teach her to live **independently**, her *social network* suffered because of being in hospital for such a length of time. She found that because she had been confined to the hospital she had lost touch with a lot of friends. Although Isabel now has a diverse *social network* she also went through a period of depression as she came to terms with her injury and this caused her to become introverted and not make the effort to keep in touch with her friends.

I lost touch with a lot of people while I was in hospital – three months is a long time, and I was too screwed up to make an effort to keep in contact. (Isabel)

Most people with an SCI in developed countries have had access to rehabilitation, which is beneficial as it teaches a person to be self-sufficient and enhances their **independence**, but rehabilitation also takes at least three months to complete. Three months is a long time to be restricted to a hospital and this can lead to a degradation of that person's *social network*.

Since a person who experiences an SCI is usually confined to hospital for about three months, the Internet can provide a link to the outside world. Providing a place on the Internet which can foster *social networks* could be beneficial for people with an SCI. A virtual community can provide a link to others with an SCI (Koh & Kim, 2003) as a virtual community is bound together by a common bond (Preece, 2001), which in this case is their SCI.

Fostering previous relationships with people in a person's *social network* as well as fostering new relationships could be beneficial for this group of people. The results for this study could show that the areas that need to be fostered for people with an SCI are friends and family as well as increasing their *social network* to include others with disabilities. Increasing a person's *social network* provides them with the resources that they may require enhancing their **independence**. One way of broadening a person's *social network* is to provide them with access to a virtual community that encourages the development of a *social network*. Isabel commented on how the Internet assisted her:

A few months down the line, I got in touch with some other spinally injured people through a website, and kept in touch with them via MSN. That was easy, as I didn't have to leave the house, or show people that I cried all the time. (Isabel)

Isabel found that talking to people through the Internet helped her to get through her depression. Once she had recovered from depression she found that it was easier to go out and take part in social interaction. She now has a very broad *social network*, which was discussed earlier in this section. She also seems to be socially engaged, thus enhancing her **independence**.

4.1.3 Summary of RQ 1

The themes of **dysfunctional relationships**, **social isolation** and **dependence** were derived from discussion about the various *social networks* of the participants in this study. Since a newly injured person usually has to spend a long period of time in hospital, a virtual community could be used to keep the injured person in contact with their *social network*. A virtual community could also bring together other people with an SCI and thus newly injured people would be able to add others with an SCI to their *social network*. Once the person has been discharged the virtual community could be used to keep in contact with their *social network* until they are ready and able to interact socially within the community.

4.2 RQ 2. What role does social participation have for people with an SCI?

While exploring research question 2, *social participation* was found to be anything that the participant did to interact with other people on a social level. *Social participation* can be obtained from sport, and can include leisure activities such as going to the cinema with members of a *social network*, or interacting with colleagues at work. Thus *social participation* consisted of 'leisure', 'sport' and 'work' (Figure 3). Based on these social activities the following themes are discussed in the following section: 1) **common ground** 2) **confidence** and 3) **control**.

4.2.1 Focus Group and Interviews

The focus group and interview members discussed their *social participation* as mainly being obtained from 'sport'. Some of them also interacted in other social areas, which were grouped into the code of 'leisure'. The categories for the focus group data under *social participation* produced the themes of **common ground** and **confidence**.

Sarah who has been injured for about 20 years described how she fully immersed herself in disabled sports and built up her *social network* through sports.

I'm here (the recreation centre) usually nearly everyday except for weekends during the season, usually on the weekends you're off doing something, either

home games or away games or glider camps and stuff like that. So a lot of my social network is through wheelchair sports because I've been doing it for so many years. (Sarah)

Sarah may have found that building her *social network* through *social participation*, more specifically through sports, meant that the people within her *social network* had sport in common. Thus she could spend time with like-minded people. Sports could provide a **common ground** for building relationships between people within the team and strengthening the *social network* through the *social participation*.

James also discussed his *social participation* as sport, but he also commented on the leisure activities that he undertook in his spare time and seems to be **confident** in himself.

I play some basketball and things; I go out clubbing every now and then. When it fits the budget... I don't mind going clubbing by myself sometimes, but I usually go out with one of the guys from basketball. We both have fun I guess. We just go out and have a laugh with lots of lights on our wheelchairs and generally be attention seeking. (James)

Sport is said to give a person confidence and a sense of self worth (Levins, Redenbach, & Dyck, 2004). James may get his confidence to go out into the world and be 'attention seeking' from being part of the sports team.

The participants in the focus group and interviews used their participation in social activities to maintain and broaden their *social networks*. *Social participation* in sporting activities encourages a healthy lifestyle as they are exercising and interacting socially, thus *social participation* is associated with the way that a person rates his or her health (Hyypä & Mäki, 2003).

Sports can also provide **common ground** between the team members and bring together like-minded people. Being part of a sporting team can increase an individual's **confidence** in themselves. It could be beneficial to find new ways of encouraging *social participation* within the SCI community to increase their health and thus reduce the strain, which they may place, on the health system. A virtual community could provide information about sporting activities and can provide areas for discussion, which in turn fosters avenues for *social participation*.

4.2.2 Discussion Board

In comparison to the focus group and interview data the online discussion board showed that there are activities other than sport that participants reported to undertake socially. The discussion board data produced the theme of **control**.

Kate's current *social participation* revolves around exercise at the gym. She also commented excitedly about getting a car, which she may use to get more involved in social activities. It may also provide her with more **control** over her life.

I go to the gym every Saturday and spend the day there weight lifting, walking and standing. I get my car soon! (Kate)

Kate's enthusiasm for getting her car may mean that she is able to participate in more activities giving her a stronger sense of **control**. Levins, Redenbach and Dyck (2004) found that participating in social activities should reduce the effect of environmental (e.g. steps) and attitudinal barriers for people with an SCI. Even though Kate does not offer further comment about her car, a lack of access to transportation may limit her social activity. Therefore for those people with an SCI who are without transportation or have limited mobility, the Internet could provide an avenue for *social participation* because by its very nature it is accessible at any time from the comfort of their own homes. This provides strong support for the use of a virtual community to raise social engagement for people with an SCI and thus QOL. A chat room as one aspect of a virtual community could provide a way for members to interact socially without the need for transportation.

In comparison, Mike felt that it takes more effort to be social because of the wheelchair, but it is not impossible. More planning is required to participate in social activities, and the ability to think laterally about the way in which a problem is tackled is often needed. These things that Mike feels are required are aspects of **control**, they give the person a sense of **control** over their lives.

I feel that its more of a effort to be social but not impossible you must just know where you going before the time and improvise, for example going to clubs isn't always accessible but that's when you get your friend to help you up, sometimes I get on my friends back and he carries me up its fun. (Mike)

To overcome socialising in inaccessible areas, Isabel, one of the discussion board participants discussed inviting her friends to her house, which has been adapted to suit her needs. By Isabel inviting her friends to her house she is **controlling** her surroundings and ensuring that she is comfortable. An active social life for a person with an SCI is beneficial because it has been linked to better health (Hyypä & Mäki, 2003), more control (Boschen, Tonack, & Gargaro, 2003) and reduced feelings of isolation (Houlihan et al., 2003). Thus, finding new ways of overcoming barriers to participating in social activities would be beneficial for people with an SCI. A virtual community could include information about access to social areas and could provide forums for shared discussion of the barriers to *social participation* and ways of overcoming them. This type of information can provide ways that people with an SCI can **control** the barriers that they may encounter to *social participation*. As such, virtual communities can encourage *social participation* both online and offline (Bargh & McKenna, 2004).

4.2.3 Summary of RQ 2

Social participation can provide a way of broadening a person's *social network*. People can participate in social activities with friends and family to maintain their relationships. All of the focus group and interview participants used sport as the main avenue for *social participation*, possibly because it provided them with **common ground** and instilled **confidence**. The members of the online discussion board interacted with friends and family through leisure activities for the most part and most of them did not discuss taking part in sporting activities, but seem to need to have some semblance of **control** over their lives.

Since an SCI provides barriers in the community, for example through lack of access which is discussed in section 4.4.3, the use of a virtual community could provide opportunities for people to take part in *social participation*, by providing avenues for like-minded people who have **common ground** to interact. This could instil **confidence** in the members of the virtual community, and could provide information for gaining **control** of their lives. A virtual community could provide an area for members to enter into a chat room, which can provide the avenue for *social participation* to take place. The virtual community could also provide information through links about sporting activities or venues for taking part in leisure activities.

4.3 RQ 3. Do people living with an SCI feel socially supported?

Through the exploration of research question 3, *social support* was found to be the emotional, physical and spiritual support that people with an SCI can obtain to lead a happy and fulfilling life, which coincides with Bath and Gardiner's (2005) interpretation of *social support*. *Social support* was grouped into the categories of 'support from their social network', 'support from social participation' and 'reciprocity'. People living with an SCI gained 'support from their social network' by communicating with the members of their *social network* to varying degrees. Support was obtained from *social participation* by providing a setting to be able to discuss issues, along with keeping people living with an SCI entertained and happy. 'Reciprocity' came from the participants saying that they contacted newly injured people to provide some source of support, because they may have felt that they needed this kind of interaction when they were first injured or they had received this kind of support and felt it had been invaluable. Based on the category of *social support* the following themes are discussed in the following sections: 1) **assurance** 2) **expectations** and 3) **understanding**.

4.3.1 Focus Group and Interviews

The participants in the focus group and interviews all discussed going back to the SCI units to encourage people that have been newly injured. They wanted to show that there is life outside the spinal unit and provide reciprocity for the people who were in the spinal unit. Sources of support for the participants in the focus group and interviews were their friends and their families. The themes produced by the data from the focus groups that were connected to *social support* were **assurance** and **expectations**.

Richard discussed reciprocity as the process of providing support for people who have a new SCI to show them that there is life after an SCI. He describes one of the times that he went to a Spinal Unit to see some of the in-patients.

There were three guys in the spinal unit and they were in their chairs the last time I went there. The physios [Physiotherapists] and the OT's [Occupational Therapists] were teaching them how to use their chairs and stuff. They were so scared of falling out that they weren't really doing anything, so I pulled a wheelie in front of them. Inevitably I was showing off and the chair went backwards so I fell out and the chair went the other way, but it showed them that you could fall out and get back in again without too much trouble. So I

went up to one of them and tipped him out of his chair and he said "you bastard you tipped me out of my chair." and I said "yep and now crawl over here like this and try and climb in." and he was like "no I cant do that." and I said "why? I just did." Eventually he decided to do it and he showed himself that he could do it. (Richard)

This incident shows that support can be provided to people who are newly injured by showing them that it is possible to do things and look past their injury, through reciprocal support, thus providing them with **assurance**. A virtual community could provide reciprocal support; for example, in this case, a member could load a video onto the website to show how to get into and out of a wheelchair.

The participants in the focus group and interviews may seek reciprocity because they may have received reciprocity during their time in hospital and felt that it was beneficial and wanted to provide the same sort of support to others. Or, the participants may not have received reciprocity but may have felt that this kind of support would have been beneficial for them, thus wanted to provide **assurance** to others in similar situations. Reciprocity for people with an SCI has been found to be beneficial (Rintala, Young, Hart, & Fuhrer, 1994) as it provides psychological well-being and encourages mobility and independence. A virtual community could be an apt way of giving and receiving reciprocity because of the ease of access there is to the Internet. A virtual community could make it easier to meet other people living with an SCI who are experienced and have a large knowledge base about dealing with an SCI long term, thus they could provide others with **assurance**.

Another participant found there were advantages to discussing problems with other people who live with an SCI. Any issues that are encountered in everyday life can be discussed with others, which widens and strengthens their *social network*. Other people with an SCI have different **expectations** than the **expectations** that able-bodied people have of people with disabilities.

I've got information about different things they've [others with spinal injuries] used and do that I never would have thought of, and they know people, and you know people. So you can get in touch with other people. So you have lots of people to talk to when you need something. (Sarah)

People with an SCI **expect** other people with SCIs to do anything and everything that they are able to, but able-bodied people seem to **expect** very little from people with disabilities.

A study by Sherman, DeVinney and Sperling (2004) found that peer support from other people with an SCI ended within the first year after injury for the majority of participants.

A virtual community could be a good tool to encourage peer support for longer periods of time. A virtual community can provide an area where the members can post comments to one another, which means that they can add comments at anytime which makes the community more accessible and the likelihood of people who are a long time post injury is higher.

All of the participants in this study discussed widening their *social network* to include at least one or two persons with an SCI (to help with the **expectations** that can be imposed upon people with disabilities) and most of the participants had been injured for more than five years. Sherman, DeVinney and Sperling's (2004) study discussed the advantages of peer support, as encouraging independence, raising their expectations about how they live their lives and providing support for any problems that may arise. The fact that they feel that this relationship and avenue of support ends after a year is contradicted by my study. The possible reason for this is that the participants in this study were young and thus were going through life changing events, and they needed the support of others with an SCI who had already been through these events to discuss the best ways in which to tackle the event. The participants may have found that creating a wide varied *social network* increases the chance of at least one of the members of their *social network* being able to provide support. *Social support* from others with an SCI may be sought throughout the life of a person with an SCI, which could be provided by a virtual community. This is just like able-bodied people who also discuss issues that arise in life to share their experiences and try and find the easiest way to go through life happy and content, but the difference is that the SCI may produce specific life events.

4.3.2 Discussion Board

The people who discussed support on the online discussion board also discussed the benefits of *social support* from other people with an SCI. Some of the participants felt that they were well supported by friends, family and members of the community, where as others felt that they were not as well supported. The theme produced from the code of *social support* for the discussion board data was **understanding**.

Reciprocity was found in a discussion with Kate who found that she got support from other people with an SCI. She finds they help her deal with any problems that she comes across because of the unspoken **understanding** that there is between them, which is mirrored by the study by Sherman, DeVinney and Sperling (2004).

*I have like almost 20 people on my phone with spinal injury, I find sometimes when I am going through the spinal injury problems I talk to them often.
(Kate)*

People with an SCI may find that getting support from others with the same affliction is highly beneficial because they may have been in the same kind of situation. This kind of support is easily provided through online technologies such as a virtual community. People with an SCI have an unspoken **understanding** of each other when it comes to bladder and bowel control and other issues that have to be tackled on a day-to-day basis. Thus there may be a common bond produced between people with an SCI. People who have high levels of *social support* and are happy with their *social network* have reported high levels of life satisfaction (Fuhrer, Rintala, Hart, Clearman, & Young, 1992).

Sarah feels supported by her General Practitioner (GP) and the other medical professionals at the surgery that she uses, but she also strives to be as independent as possible. Whenever she goes to see her GP she usually knows what she wants and needs so that she is in control of her own care. In this way, her GP would be classified as a member of her *social network*.

I am lucky enough to have a very supportive GP and a lovely nurse at my surgery, so that I have plenty of support when I need it. I quite like being self-caring - I determine the majority of my own care, and like to be very active in the treatment decisions made about me. I am more likely to go to the GP knowing what I want/need, or wanting to discuss something, than for them to tell me what they've decided about my care. (Sarah)

A *social network*, which includes health professionals, friends, family and others with an SCI and other sources that are found in the general community, provide the person with a support network that can encourage a happy health lifestyle. This is supported by Kana'iaupuni, Donato, Thompson-Colón and Stainback (2005) who state that a large *social network* is linked to higher levels of support.

When people with an SCI participate in social activities they can also feel supported; for example, when they try to participate in social activities that take place in inaccessible areas. Lizzy discusses the ways that her friends and work colleagues support her and make it possible for her to take part in social activities with a little help from her friends.

A friend of mine [Cardiologist I work with] is having a Halloween party. He said that I have to go to it but he had to warn me that he had stairs in the front of his house. As I was about to say I didn't have a problem with a few hotties helping me up the stairs, he said "but that's not a problem. I'll fling ya over my shoulder!" (Lizzy)

People with an SCI want to be able to take part in social activities with their friends and family and for the most part they will usually go to any lengths that are required to take part. Lizzy seems to have built up an **understanding** between herself and the people in her *social network*. Kate is the only participant who seems to contradict this, as shown in Section 4.1.2.

Social support is provided by all of the members of a person's *social network*, each member provides the support to a differing degree. All of the participants in the focus group and interviews felt that they were supported and enjoyed providing support in the form of reciprocity for others with an SCI. In comparison, only a few of the participants on the discussion board commented on providing reciprocal support. On the discussion board the participants also discussed obtaining support from medical personnel as well as friends and family. This was not commented on in the interviews. Perhaps because the participants on the discussion board have been injured for shorter times they are still attached to their medical personnel.

The Internet could be used as a source of *social support* because of its popularity among young adults (Kofman, 2006) and provides a way of contacting others with an SCI as well as family and friends. The use of the Internet through virtual communities can lessen feelings of depression and increase feelings of self worth (Drainoni et al., 2004). Virtual communities could provide peer support for people with an SCI and could provide a forum for people with an SCI to discuss any issues that they come across in the community (Houlihan et al., 2003).

4.3.3 Summary of RQ 3

The participants found that their *social networks*, as well as taking part in social activities, were used to obtain *social support*. One of the other ways that the participants found that they obtained support was participating in reciprocal interaction with people who had new SCIs. This reciprocal interaction was found to be beneficial for both the participant and the newly injured person because **reassurance** and **understanding** can be provided. The **expectations** of others with an SCI can encourage greater interaction. Reciprocal support is provided between two people with an SCI, who discuss issues that may arise because of their SCI.

Virtual communities could be a valuable tool in linking people who have lived in the community for long periods of time, to people that have been injured recently and are still in hospital, thus provided an avenue for reciprocal support to take place. A virtual community providing ways of bring people with old and new SCIs together provided **understanding** for the members, which helps **reassure** new SCIs. A virtual community could provide reciprocal support between two people who may be in different countries and their only link is their SCI.

4.4 RQ 4. Are there other aspects for people living with an SCI that affect social engagement?

Some of the themes that emerged from the data could not be placed within the three categories outlined by Bath and Gardiner (2005). The themes **fear of acceptance**, **social stigma**, **access**, **independence** and the **Internet** (Table 4) can be linked together. **Fear of acceptance** may occur because people have seen or experienced **social stigma**. **Social stigma** could be linked to a lack of **access** and thus a reduction of **independence**. If there is a lack of acceptance within the community, the community may not think about providing access for these people. Due to **social stigma**, **inaccessibility**, **fear of acceptance** and decreased **independence**, people in this situation may turn to the use of the **Internet**.

Table 4. The other categories produced by the data

Social Stigma
Access
Fear of Acceptance
Independence
Internet

4.4.1 Social Stigma

The theme of **social stigma** includes people staring at the participant, and talking and treating them in a specific way because of the wheelchair. This theme arose from both the online discussion board and from the participants in the focus group and interviews.

Social stigma usually occurs when the wheelchair is seen and thus the person in the wheelchair is perceived to be treated differently. Sarah, one of the interviewees, found that people who are able-bodied initially see the wheelchair before they see the person in the wheelchair for whom they are.

I think that AB's [able-bodied people] known as AB's for me. I think sometimes they see the chair. Like if your first meeting me, I think they see the chair first and later they will be OK, but I think it takes them a while to see the person first. (Sarah)

The reason that this occurs could be due to a lack of exposure and ignorance towards people in wheelchairs and thus the able-bodied person may not know the best way to treat people in wheelchairs. A chat room within a virtual community could provide access to discussion about experiences with **social stigma** and ways to combat it. Experiencing **social stigma** can be difficult and can discourage a person from being an active participant in the community. Being part of a group that experiences **social stigma** leads its members within this group to seek out people with similar conditions due to the unspoken understanding that occurs (Davison, Pennebaker, & Dickerson, 2000). In this study the participants in the online discussion board who had only been injured for a short time discussed the need to avoid over-populated places and thus possibly avoiding the **social stigma** that they may experience in populated areas. A virtual community could help with overcoming the fear that people seem to have when they have a new SCI. Mainly a virtual community could encourage people with an SCI to discuss ways in which to encourage people who are able-bodied to see the person before they see the chair. It may be that able-

bodied people are just too scared of saying the wrong thing to the person in the wheelchair, therefore building the person with an SCI's confidence could stimulate them to approach able-bodied people first.

The use of the Internet through virtual communities could inform people about what to expect from meeting new people and ways of coping with **social stigma**. Some people who are living with an SCI may be able to provide ways of overcoming the **social stigma** that they experience. For example, Isabel discusses her way of 'breaking the ice':

I used to wink at people if they stared at me, which either made them stop staring out of embarrassment, or say hello to me, which helped me get out of the house. (Isabel)

Isabel showed that using a virtual community to discuss ways of 'breaking the ice' with people in the community could reduce feelings of isolation and encourage social interaction. This could encourage people living in the community with an SCI to engage socially.

4.4.2 Fear of Acceptance

This category was only found from the online discussion board data and is tied to **social stigma**. A person with an SCI could feel that their friends, family and community will not accept them. This could be due to how they perceived people in wheelchairs before their accidents or they may have experienced rejection from a member of their *social network* soon after their accident.

My boyfriend dumped me just after my accident, I guess he just couldn't handle everything and decided to end it instead of work through it. This made me very depressed and I felt that everyone would treat me this way. I am no longer friends with a lot of the people that I knew before my accident. (Kate)

The participants in the focus group and interviews had been injured for longer periods of time than most of the discussion board participants, thus may not remember the fear that they may have experienced while they were in hospital or the few years after being discharged. Due to the focus group and interview participants mainly being injured at a

young age, their parents may have tried to shelter them from experiencing **social stigma** and thus they never felt that they were not accepted.

The participants in the focus group and interviews were all from Perth, Australia, which may have impacted on how accepted they felt. Australia is a developed nation and has laws against discrimination (Disability Discrimination Act, 1992) and thus the community has been informed to treat people with disabilities as equals. In comparison, the people who used the online discussion board were from different locations in the world and included some members from developing countries, where people with disabilities have little to no rights (because of a lack of enforced legislation) and thus they may experience a lot more **social stigma** and be less acceptable to society. In places like Uganda if an able-bodied person sees a person in a wheelchair they automatically think that they are not able to look after themselves, purely because their body differs from that of the stereotypical perception of a 'normal' body (Lwanga-Ntale, 2003).

People with an SCI could meet online in a virtual community, which would allow them to discuss their fear. This may reduce their fears as they may no longer feel isolated and have the ability to discuss their fears rationally. Having the ability to discuss such issues may cause solutions to arise which may make people with an SCI feel more comfortable.

4.4.3 Access

This theme discusses the issue of **access** to buildings and especially **access** to toilet facilities, by people who have to use a wheelchair. In the United Kingdom in the mid 1990's the government pushed part 'M' of the building code (Crown, 2003, 2004) to include residential housing. This would provide independent **access** to residential dwellings for wheelchair users. Thus any new house that is erected is encouraged to provide **access** for wheelchair users (Crown, 2003, 2004). In Australia, a report has been developed (Parken et al., 2005) that is suggesting to the government that a similar policy to that found in the UK would be beneficial for the Australian community. The discussion board participants and the focus group and interview participants discussed **access** to facilities as being difficult.

Richard discussed **access** to toilets extensively. He seemed to find that doorways are often too small to manoeuvre a wheelchair through, which frustrated him.

Toilets and the size of the doors in this country, they are so small for no reason, this is Australia there's plenty of land come on. I went to a mate's house and he has three toilets and I can't get into a single one of them. I think there just saving timber or something, sometimes they are just a bit tight and you just have to say sorry mate but the paint is coming off your doorframe. Also when I go out the toilets are dirty, its just really dirty. When you go out clubbing there's no lock on the disabled toilet doors and a lot of people try to use them. I think that it would be better if the bouncers or someone had the key to it and you had to go and get it opened to be able to use it. (Richard)

He commented on finding it especially frustrating at his friends' houses, therefore this may cause him to be reluctant to visit his friends in their homes. One way of getting round the problem of the small doorways to cubicle toilets, and most toilets in private houses, is to reduce the size of the wheelchair. Sarah discussed in her interview, how she has made sure that her chair fits through these toilet doors.

Those doors [toilet doors] are 620[mm] my chair fits through 620[mm] doors, my old chair didn't but I made this one so that it would fit through 620mm doors, but if you do have a wider chair then you have to find a disabled toilet otherwise you cant get in. I can get into normal cubicles but before I couldn't but those doors are annoying. (Sarah)

In general, the widths of wheelchairs are about 700mm, which is too wide for the toilet doors in most Australian houses according to Sarah. The size of the wheelchair is entirely dependent on the size of the user to ensure maximum comfort. Not having **access** to toilets could hamper any effort to socially engage. Along with the paralysis of legs and arms that can happen with an SCI, bladder and bowel can be affected and may not function as most able-bodied bodies do (Widerstrom-Noga, Felipe-Cuervo, Bronton, Duncan, & Yezierski, 1999). Having **access** to toilet facilities can be very important for some people with an SCI; not having this **access** may reduce the frequency with which a person with an SCI may visit their friends and family. Using the Internet for interaction means that a person with an SCI can still participate socially but do not have to leave the comfort of their own homes where they know that they have easy **access** to toilet facilities. A virtual community could also provide information about places that have **accessible** facilities, which could encourage people with an SCI to socialise in these areas. If there were a chat room as one aspect of the virtual community this could be used by the members to discuss ways around

problems with **access**, as well as notifying the members of **accessible** places for participating in social activities.

4.4.4 Independence

A person who acquires an SCI goes into a spinal unit for rehabilitation so that they can develop a knowledge that encourages **independence**. “The first requirement of disabled people in participating as equal citizens within the community is a home which is suited to them, together with control over the necessary help they require to live independently” (Swain, Finkelstein, French, & Oliver, 1993).

Independence of a person in a wheelchair is dependent on their ability due to their level of injury, but they also rely on the **accessibility** of the world around them. If they find the world around them **inaccessible** they may be less likely to interact within it. During rehabilitation people with an SCI are taught wheelchair skills, which could help them to overcome a relatively **inaccessible** world. Wheelchair skills show users how to get into and out of the wheelchair on a basic level, but it can also teach things as complex as going up and down flights of stairs in a wheelchair. These skills could enable someone with an SCI to overcome even some of the most hostile and **inaccessible** environments. In some areas of the world mainly in parts of Africa (Cornick, 2001) wheelchair skills are not taught in spinal units, which means that people in these areas of the world may not have the ability to interact socially. They may feel restricted to their chairs and have problems dealing with **inaccessible** areas.

Isabel, who lives in Europe, says that she felt that the biggest change for her was when she was given a wheelchair that was light enough to give her **independence** and she was then able to do everything she had been taught through wheelchair skills; go up hills/kerbs and use escalators.

The biggest change for me was getting a decent wheelchair - all of a sudden, I could get in the car without help, could see myself in the mirror, rather than just the chair, and generally take an interest in myself again. I could also get around much more easily, going up hills/kerbs/escalators in this wonderful light wheelchair. (Isabel)

The participants in the focus group and interviews and the participants in the online discussion board commented on the need to have **independence** and the richness that being independent brought to their lives. A virtual community can be used to foster **independence**; people with an SCI could discuss **access** to places and ways around **inaccessible** places. This source of support could be used to discuss any problems that they may come across in their day-to-day lives that could hamper their **independence**.

4.4.5 Internet

One of the difficulties that people with an SCI often have is accurate and efficient control of pointing devices (Keates, Hwang, Langdon, Clarkson, & Robinson, 2002). Using the mouse and keyboard to interact is a large component of graphical user interfaces (GUI) (Surdilovic & Zhang, 2006). It is possible for people with impaired movement and control to obtain assistive technologies to aid them in interaction with a GUI interface. These technologies include 'on-screen keyboards, head-controlled pointing as well as speech-recognition/voice control input devices' (Surdilovic & Zhang, 2006, p. 87). Therefore there is a need for development of these technologies to work with website designers and developers so that the assistive technologies meet the needs of the users. Assistive technologies are an integral aspect of the provision of independence and self-care for people with motor impairments (Carlson & Ehrlich, 2005). For example quadriplegics use assistive technologies to move the mouse on the screen with their eyes or head.

The main barriers that people with motor function impairments and use assistive technologies usually encounter according to Larson and Gips (2003) are as follows:

- The buttons on the screen too small and people lack the fine control necessary to use them by moving their eyes or head.
- The links can be too close together which can cause the selection of the wrong link inadvertently.
- A link can be selected while the person is still looking through a webpage because the technologies select the links by hovering over a button/link.
- Some websites require more than just a left click to navigate through the site.
- The text on the webpage may not be distinguishable due to vision problems

Virtual communities need to be designed with these assistive technologies in mind so that they provide access for people with disabilities. The participants in this research all had access to the **Internet** in some capacity and did not require the use of assistive technologies.

All the participants discussed the theme of **Internet** use since it was one of the aspects of this study and the participants were questioned about their current usage of the **Internet**. They discussed how and why they currently use the **Internet**. All of the participants said that they used the **Internet** to keep in touch with people via email, which is a form of social engagement, by keeping in touch with their *social network*.

The participants in the focus group and interviews reported to use the **Internet** to keep in contact with family and friends through email. It has also been used to contact old friends that some of the participants may have lost contact with. They found their old friends through social websites such as MySpace (<http://www.myspace.com>) and Facebook (<http://www.facebook.com>). All of the participants in this study admitted to using the Internet in some way. The case may have been that all of the participants were paraplegics and as such did not have problems with upper-body motor function. This meant that the use of the **Internet** would not be hampered by the use of assistive technologies. This was the case for the face-to-face participants in this research, but the participants in the online discussion board were not questioned about the specific aspects of their SCI.

Sarah discussed her use of the **Internet** as beneficial for keeping in touch with friends due to moving around a lot.

I was born in New South Wales lived there till I was nine then I moved here for five years and then to Queensland and was there for like four or five years and now I'm back here so like all the friends I've made all over I've kept in contact through emails or MSN and stuff like that or lost contact with them, but I've found a whole bunch of people I used to go to school with in Perth when I first lived here through MySpace. (Sarah)

The participants also discussed the use of the **Internet** as a source of support. James talked about some support that he found on the **Internet**.

I've been to a few discussion boards, and I personally haven't really been involved in that sort of thing but its good to be able to read through, and see what other people are saying. It's even good just to find information about different things. I've spoken to a few people that have recently had accidents and I guess it's just nice to be able to speak to somebody whenever they feel like talking. Just knowing that they can ask questions and they will get an answer back that is relevant to them. Also the fact that you can be anonymous I think helps because some questions about disabilities are a bit personal. So they probably don't want to ask it face-to-face, but still want and get an honest relevant answer, which is good. (James)

He **accessed** a few different discussion boards to see if there were other people who had gone through what he was going through. He could then explore what they had done to combat the problem. He likes the way the **Internet** can be used at the users own leisure and that it can be anonymous.

People with an SCI may like to use the **Internet** as a social medium because it means that they do not have to leave the comfort of their own homes 24 hours a day 7 days a week (Burkell, Wolfe, Potter, & Jutai, 2006). By developing relationships online they may be encouraged to develop relationships offline and socially engage within the community. They can also remain anonymous and thus can distance themselves from **social stigma** if it occurs online. Virtual communities have been found to decrease feelings of depression and increase feelings of self worth (Drainoni et al., 2004).

One of the participants discussed what she would have liked while she was in the SCI hospital;

It would have been nice to meet a wider range of people (SIU [Spinal Injury Unit] 'graduates') while I was in the SIU. There were few people who came back, and of those few, most were not in a very healthy state, either physically or psychologically. It sounds rather hypocritical, as I wouldn't want to go back myself, but I would have liked to meet 'me' as I am now, 5 years ago. (Isabel)

She found that only a few people came back to the hospital and of the people that did they were usually in poor states of health. She felt that she would have liked to have **access** to people who have been living in the community for some time after being discharged from hospital. A virtual community could provide this kind of support without making people return to the SCI hospital. The virtual community could provide **access** to people who have

lived in the community for varying lengths of time, thus people that are newly injured can discuss what it is like to live with such a life altering injury.

4.4.6 Summary of RQ 4

Other reasons a person with an SCI may find it difficult to interact socially are largely due to the way able-bodied people treat them (**social stigma**) and the **accessibility** of the world around them, which can cause people to **fear acceptance**. People with an SCI have to make sure that where they are going is **accessible** or they may have to sacrifice parts of their **independence**. They may also need to ensure that there is **access** to toilet facilities or it could lead to an embarrassing situation. Overcoming physical obstacles such as stairs and **access** to bathroom facilities may deter people with an SCI from taking part in social activities. Most of the participants had ways of overcoming **social stigma** which they had all experienced and thus did not feel like it affected them. However there may be others that did not take part in this research that felt that the **social stigma** attached to being in a wheelchair hampered their experiences of social interactions. Due to the experience of **social stigma**, **inaccessibility**, **fear of acceptance** and decreased **independence**, people with an SCI may turn to the use of the **Internet** to discuss issues with like-minded people.

4.5 Possible features for a virtual community

Given that the findings from this study show that a virtual community could be apt for people with an SCI, the development of heuristics could be beneficial, and as such would need to be researched further. The following list could depict aspects of a virtual community that could encourage social engagement by broadening a *social network*, increasing *social participation* and providing *social support* for people with an SCI. The virtual community could also provide avenues for its members to discuss access and experiences of social stigma.

- A chat room – this could be used to participate socially from the comfort of their homes.
- Links to information about sporting activities for the disabled or venues for taking part in leisure activities.

- Videos of wheelchair skills – could be uploaded to websites such as “YouTube” (<http://www.youtube.com>) and linked to the virtual community to provide reciprocal support.
- A discussion board which allows posts to be placed at anytime, which can provide peer support for people with both new and old SCIs.
- Travel information (Access) – this could provide information about accessible places to socialise.

Four current websites were examined to see if they contained any or all of the suggested features for a virtual community. The website that were examined focused on disability and in some cases more specifically on SCI.

The first virtual community examined was Youreable.com (<http://www.youreable.com>), which targets anyone with a disability. This community provides information connected to disabilities along with a discussion board where the members can discuss any issues they may have. In comparison disabled-world (<http://www.disabled-world.com>), which targets the same group of people, provides both of these aspects, but also provides a chat room area where people can discuss issues in real time.

Disaboom (<http://www.disaboom.com>) is a virtual community, which is created for all disabilities but also has the option to focus on a specific disability. This community provides information about travel, health related topics, new research and jobs for each type of disability. There are options to discuss health topics connected to a specific disability as well as a general discussion board about disability. A moderated chat room is also present on the website.

Spinal-injury.net (<http://www.spinal-injury.net>) is a virtual community specifically targeting people with an SCI. They provide a discussion board, a chat room, links to information about research, fact sheets, travel, access and sporting information. They include a section on mobility, which currently provides information about driving cars, which is a form of providing independence. This section does not currently include wheelchair skills, but with this inclusion this virtual community could provide all of the aspects that have been suggested by this research.

4.6 Summary of Findings

A virtual community for people with an SCI would create a 'community of circumstance' (Cummings, Heeks, & Huysman, 2006) because they are being brought together by their injury. This is supported by all of the participants in this study having discussed widening their *social network* to include people with an SCI.

The results from this study show that a virtual community built specifically for people with an SCI could provide avenues for social interaction, which could provide *social support* through *social participation* and broadening their *social networks*. For a virtual community to maintain itself and to grow it needs to target the specific needs of the users and provide them with the experiences and the benefits that they require (Butler, 2001). A virtual community can only survive as long as members use and participate within the group; individuals only remain interested in the group as long as their needs are being met (Arguello et al., 2006). A virtual community is particularly apt for this group of people because they may experience barriers such as a lack of **access** within the community since a virtual community is **accessible** from the safety and comfort of their own houses 24 hours a day, it provides an **accessible** way of participating socially.

For an SCI community to be successful members need to be able to discuss issues with others with the same type of affliction that they may have gone through and a virtual community could provide an avenue for achieving this type of support. The virtual community could provide avenues for people to participate socially offline as well as online. The nature of a virtual community is that the members discuss issues between themselves and thus create *social participation*. People are enjoying the blurring of the line between online and offline communication and interaction (Churchill, Girgensohn, Nelson, & Lee, 2004), as online communities are starting to stimulate participation in offline communities. Thus, creating a virtual community that encourages social interaction between friends, family and other people with an SCI as well as providing information about social gatherings could be beneficial for a person with an SCI.

Chapter 5 Conclusion

5.1 Conclusion

This research showed that Virtual Communities could be beneficial for a person's *social network* because it provides a way of maintaining and expanding a person's *social network* while they are in hospital and upon discharge. This expansion in hospital is most likely to be made up of other people with an SCI and this was identified as a key requirement for social networking.

People who live with an SCI tend to turn to their friends, family and other people with an SCI for support and social interaction. These are the types of relationships that need to be fostered and encouraged to grow. Although this study did not test if the Internet was beneficial for social engagement after an SCI, it identified that the Internet could play a key role in social engagement based on the current experiences of the participants.

This study found that active *social participation*, such as participating in sporting activities, provides an avenue for people to be social, remain healthy and develop their social engagement. Participation in social activities, like going to friends' houses or restaurants, helped people with an SCI to feel happy and it reduced their depressive feelings.

Even given the small sample every member that participated in this research felt that they were supported and enjoyed providing support in the form of reciprocity for other people with an SCI. From the discussion board, it was established that reciprocal support was certainly a process that was highly effective. Overall, the study found that reciprocal support was something that was well received and considered to be a very important activity to both give and receive.

The social stigma from able-bodied individuals was found to be a hindrance to the ability of a person with an SCI to participate and engage in social activities. This, combined with the lack of wheelchair accessibility found within the general community, has led to a fear of discrimination. Although this study has found that those people with an SCI who are

actively engaging in social activities (such as sports) are not suffering from this discrimination, it is something that they all identified as having overcome rather than never received. This study found that receiving rich levels of *social support*, participation and networking was the primary reason for overcoming this stigma.

With virtual communities becoming very popular amongst young adults (Kofman, 2006) and the prevalence of SCIs occurring to people in the same age group, it is likely to target this group with the aid of the internet. By combining this finding with that of the importance of reciprocal support, it can be suggested that the development of a virtual community that provides integrated social engagement between people with an SCI would be highly beneficial to the continued rehabilitation of a person with an SCI.

5.2 Recommendations for further research

Due to the problems with recruitment the data set for this research was small. Further research may therefore be required to fully understand how a person with an SCI could use a virtual community to develop their social life.

It is beyond the scope of this thesis to discuss the use of the Internet by specific genders, but even with this small sample the results showed that women seemed to be more willing to offer support through the Internet. This is interesting to find in this research given that men have a higher injury rate than women. It would be beneficial for the SCI population, and for people who are interested in the use of the Internet as a form of support, to explore this concept.

The results from this study have shown that there are barriers within the community that hamper social engagement; this is especially prevalent in relation to access to buildings and toilet facilities. People with an SCI want to be as independent as possible and would like to be able to travel to their friends houses to participate in social interaction. It would be beneficial to the SCI population in Australia to look at the impact that lack of access to private housing has on their lives.

A virtual community could provide ways of discussing the barriers that are found in the community. A virtual community can help by providing information about the access of

facilities at venues; it may also be possible for members to post videos which can show the best ways of overcoming access problems.

The opinions of males have not been compared to females. Further research is required to establish whether there are any discrepancies between social engagement requirements of males and females.

It would be beneficial for the SCI community if heuristics were developed for the design of a virtual community for these people. Since this research has shown that a virtual community could provide the opportunity for raising social engagement and thus QOL for people with an SCI, the next step that is required is to analyse the best way in which to construct a virtual community for this group of people.

5.3 Limitations of the Study

The main limitation of this study was recruiting participants. The problems with recruitment meant that only a small number of participants took part in this study. Since the participants in the focus group and interview discussions were all found through the Western Australian Disabled Sports Association, this meant that they all took part in social activities, which could have influenced the answers that they provided for this study. Since there were no participants in the focus group and interviews that did not take part in disabled sport it was not possible to discuss the differences between being involved in disabled sport and not being involved. The participants who commented on the online discussion board were not all members of a disabled sport and thus their data provided an alternative view of social engagement, but due to the access of the Internet it raises questions about the validity and trustworthiness of the data produced. The problems and issues that are raised by the use of the Internet are outweighed by the benefits of the ease of use. The relative anonymity for the participants meant that they could talk freely about issues, which could have created inhibitions in face-to-face communication. The fact that the Internet can be accessed at the participants' leisure and from the comfort of their own home meant that the participants felt comfortable in their surroundings while participating in this research.

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Appendices

Appendix I

Information for Focus Group and Interviews

Letter to Participants in Focus Group and Interviews

Research Project: An exploration of social engagement to promote quality of life for people with a spinal cord injury: Informing the design of a virtual community.

This research project will examine the impact spinal cord injury has on a person's quality of life, specifically their social life. The information will be used to develop an understanding of people's experiences and produce a suggested format for an innovative form of support. This study is targeting people who would have had a spinal injury for at least a year and are aged between 18-35.

If you are interested in this research then you will be asked to discuss your experiences with the researcher, in a focus group with other people living with spinal cord injuries, which should last about an hour. During the focus group session you will be encouraged to share your opinions with those who have had similar experiences and who are from the same age group. You will also have the opportunity to discuss these social issues with other spinal cord injured persons through a google group at www. (The web address will be placed here once the website (google group) has been set up).

It is important for you to know that the discussions may touch on sensitive topics relating to the memory of your injury and the way in which it may have altered your life. You are free to withdraw from the research project at anytime and are not obligated to discuss any information that you do not wish to. Every effort is made to make participants feel comfortable and supported.

If the results of the research are published your identity will not be revealed, a code name will be used to refer to the data. The results produced could lead to quotes that you provide being used. The focus group meetings will be audio recorded and transcribed by the researcher. The tapes produced and any other confidential information will be stored in a locked filing cabinet and destroyed once the research project has been completed. The themes drawn from the data provided by the participants will be sent to the participants upon completion of the research.

If you would like to participate in this research please complete the consent form provided and return it to the researcher. For more information you can contact Leah Bulloch on [REDACTED] or via email leahmarb@student.ecu.edu.au. You can also contact Joe Luca or Leesa Boniface (their contact details are provided at the end of this letter). If you would like to contact an independent person who is not involved in the project please contact the research ethics officer on 63042170 or email research.ethics@ecu.edu.au.

Thank you very much for considering taking part in this study, I look forward to hearing from you.

Leah Bulloch: Researcher	Joseph Luca: Primary Supervisor	Leesa Bonniface: Secondary Supervisor
Tel: [REDACTED] Email: leahmarb@student.ecu.edu.au	Tel: (08) 93706412 Email: j.luca@ecu.edu.au	Tel: (08) 63045459 Email: l.bonniface@ecu.edu.au

The ECU Human Research Ethics Committee has approved this research project.

Informed Consent Document

*(Please complete this document and return to the researcher if you wish to participate) .
(A duplicate copy will be made and returned to the participant)*

I declare that I have read and understood the information letter provided. I have been given the opportunity to ask questions about the research and am satisfied with the answers provided. If I have any further questions I can contact the research team.

I understand that I will be taking place in a focus group meeting. I understand that all of my dialogue will be kept confidential, and will not be disclosed.

The information that I provide in the focus group meeting will only be used for the purpose of the research as outlined in the “Letter to Participants”.

I understand that I can withdraw from participating in the research at any point without the need for an explanation.

I agree to participate in this research project. I agree to the use of audio equipment during the focus group discussion.

The data collected may be used only for the purposes of this research project.

Date.....

Signature.....

Name (BLOCK CAPITALS).....

Telephone No.....

Email address.....

Leah Bulloch: Researcher	Joseph Luca: Primary Supervisor	Leesa Bonniface: Secondary Supervisor
Tel: [REDACTED]	Tel: (08) 93706412	Tel: (08) 63045459
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Instrument for Focus Group and Interviews

Social Networks

- How would you describe your social network?
- How has your SCI impacted on relationships with family and friends?
- Since SCI what issues arise when forming new friendships and/or relationships?
- What do you do to develop and maintain your social network?

Social Support

- Do other people understand what it is like to have a SCI?
- Do other people with a SCI understand?
- Do you interact with other people with a SCI now? If so, what do you like/dislike about this?
- Do you feel supported as a person with a SCI?
- How would you feel better supported?

Social Participation

- What activities are you involved in socially?
- Do you participate in sporting activities?
- What leisure activities do you undertake?

What do you think about using the Internet as a tool to develop your social contacts, participation and support?

The results from this study will be used to develop a framework for a virtual community; do you have any thoughts on this?

Research into the impact a spinal injury has on your social life.

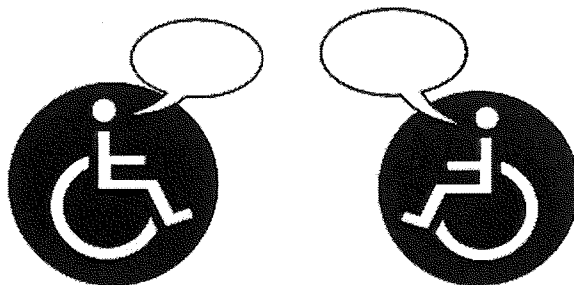
Have you had a spinal injury
for more than a year?

Are you aged between 18 and 35?

Would you like to be part of innovative research
into the impact that a spinal injury
has on your social life?

I have a spinal injury and
I am looking for people to participate
in a focus group for my research project.
Participation in this research will give you the
opportunity to discuss your opinions
among others with a spinal injury.

If you would like to participate in this research
or have any questions
please contact Leah Bulloch on [REDACTED]
or email leahmarb@student.ecu.edu.au



Appendix II

Information for discussion boards

Letter to Participants in Discussion Boards

Research Project: An exploration of social engagement to promote quality of life for people with a spinal cord injury: Informing the design of a virtual community.

This discussion board is being used as part of a research project being conducted at Edith Cowan University. This research project will examine the impact spinal cord injury has on a person’s quality of life, specifically their social life. The information will be used to develop an understanding of people’s experiences and produce a suggested format for an innovative form of support.

If you are interested in this research project please feel free to participate in the discussion within this google group. Please be aware that this group is being used for a research project and that your comments may be used by the researcher in a published paper providing you are not identifiable. In order to protect your identity online please select a nickname (code name) to use on this discussion board.


If you would like a copy of the themes that have been drawn from the data by the researcher, please send an email to the researcher. The researcher will send copies of the results produced upon completion of the research.

If you have any further questions please feel free to contact Leah Bulloch on [redacted] or via email leahmarb@student.ecu.edu.au. You can also contact Joe Luca or Leesa Bonniface (their contact details are provided below). If you would like to contact an independent person who is not involved in the project please contact the research ethics officer on (+61) (08) 63042170 or email research.ethics@ecu.edu.au.

Leah Bulloch: Researcher	Joseph Luca: Primary Supervisor	Leesa Bonniface: Secondary Supervisor
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The ECU Human Research Ethics Committee has approved this research project.

Screen shot of the face of the discussion board used

**SPINAL CORD INJURY AND SOCIAL LIFE**

Search this group

Search Groups


Home

Title of Research Project: An exploration of social engagement to promote quality of life for people with a spinal cord injury: Informing the design of a virtual community.

This discussion board is being used as part of a research project being conducted at Edith Cowan University. This research project will examine the impact spinal cord injury has on a person's quality of life, specifically their social life. The information will be used to develop an understanding of people's experiences and produce a suggested format for an innovative form of support.

If you are interested in this research project please feel free to participate in the discussion within this google group. Please be aware that this group is being used for a research project and that your comments may be used by the researcher in a published paper providing you are not identifiable. In order to protect your identity online please select a nickname (code name) to use on this discussion board.

If you would like a copy of the themes that have been drawn from the data by the researcher, please send an email to the researcher requesting this information. The researcher will send copies of the results produced upon completion of the research.

If you have any further questions please feel free to contact Leah Bulloch or  or via email leahmarb@student.ecu.edu.au. You can also contact Joe Luca or Leesa Boniface (their contact details are provided below). If you would like to contact an independent person who is not involved in the project please contact the research ethics officer on (+61) (08) 63042170 or email research_ethics@ecu.edu.au.

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The ECU Human Research Ethics Committee has approved this research project.

Discussions 5 of 23 messages view all »

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Results

By Leah - Nov 9 2007 - 1 author - 0 replies

Welcome

By Leah Bulloch - Oct 17 2007 - 4 authors - 15 replies

Hi Everyone

By Leah Bulloch - Oct 6 2007 - 2 authors - 2 replies

The Internet and socialising


By Jo - Sep 20 2007 - 2 authors - 1 reply


Your Story


By Leah - Aug 29 2007 - 1 author - 0 replies


Members 20 members view all »


+ invite members


Anjali
Member

bassu.miah@googlemail.com
Member

elvish
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leozo
Member

EasyE
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Group Info

Members: 20

Activity: Low activity

Language: English

Group categories:

Other

Health > Disabilities

Recreation

change categories

More group info »

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